

**SUPPORTING ECONOMIC STABILITY  
AND SELF-SUFFICIENCY AS AMERICANS WITH  
DISABILITIES AND THEIR FAMILIES AGE**

---

---

**HEARING**  
BEFORE THE  
**SPECIAL COMMITTEE ON AGING**  
**UNITED STATES SENATE**  
ONE HUNDRED FIFTEENTH CONGRESS

SECOND SESSION

---

WASHINGTON, DC

---

JULY 18, 2018

---

**Serial No. 115-20**

Printed for the use of the Special Committee on Aging



Available via the World Wide Web: <http://www.govinfo.gov>

---

U.S. GOVERNMENT PUBLISHING OFFICE

SPECIAL COMMITTEE ON AGING

SUSAN M. COLLINS, Maine, *Chairman*

ORRIN G. HATCH, Utah  
JEFF FLAKE, Arizona  
TIM SCOTT, South Carolina  
THOM TILLIS, North Carolina  
BOB CORKER, Tennessee  
RICHARD BURR, North Carolina  
MARCO RUBIO, Florida  
DEB FISCHER, Nebraska

ROBERT P. CASEY, JR., Pennsylvania  
BILL NELSON, Florida  
KIRSTEN E. GILLIBRAND, New York  
RICHARD BLUMENTHAL, Connecticut  
JOE DONNELLY, Indiana  
ELIZABETH WARREN, Massachusetts  
CATHERINE CORTEZ MASTO, Nevada  
DOUG JONES, Alabama

---

KEVIN KELLEY, *Majority Staff Director*  
KATE MEVIS, *Minority Staff Director*

## CONTENTS

	Page
Opening Statement of Senator Susan M. Collins, Chairman .....	1
Statement of Senator Robert P. Casey, Jr., Ranking Member .....	2

### PANEL OF WITNESSES

Kelly Nye-Lengerman, Ph.D., MSW, University of Minnesota, Institute on Community Integration, Research and Training Center on Community Liv- ing, Minneapolis, Minnesota .....	6
Benjamin Wright, Father and Business Owner, Wilmington, North Carolina ..	8
Edward Mitchell, Independent Living Specialist, Jackson, Tennessee .....	10
Jack Stollsteimer, Deputy State Treasurer for Consumer Programs, Pennsyl- vania Office of the State Treasurer, Harrisburg, Pennsylvania .....	12

### APPENDIX

#### PREPARED WITNESS STATEMENTS AND QUESTIONS FOR THE RECORD

Kelly Nye-Lengerman, Ph.D., MSW, University of Minnesota, Institute on Community Integration, Research and Training Center on Community Liv- ing, Minneapolis, Minnesota .....	34
Questions submitted for Dr. Kelly Nye-Lengerman .....	49
Benjamin Wright, Father and Business Owner, Wilmington, North Carolina ..	54
Questions submitted for Benjamin Wright .....	55
Edward Mitchell, Independent Living Specialist, Jackson, Tennessee .....	56
Questions submitted for Edward Mitchell .....	64
Jack Stollsteimer, Deputy State Treasurer for Consumer Programs, Pennsyl- vania Office of the State Treasurer, Harrisburg, Pennsylvania .....	72
Questions submitted for Jack Stollsteimer .....	73

#### ADDITIONAL STATEMENTS FOR THE RECORD

Pennsylvania Constituent Support Letters for ABLE .....	76
Joe Joyce, Chair, Autism Society of America .....	91



**SUPPORTING ECONOMIC STABILITY AND  
SELF-SUFFICIENCY AS AMERICANS WITH  
DISABILITIES AND THEIR FAMILIES AGE**

---

**WEDNESDAY, JULY 18, 2018**

U.S. SENATE,  
SPECIAL COMMITTEE ON AGING,  
*Washington, DC.*

The Committee met, pursuant to notice, at 9:31 a.m., in room SD-562, Dirksen Senate Office Building, Hon. Susan M. Collins (Chairman of the Committee) presiding.

Present: Senators Collins, Tillis, Burr, Fischer, Casey, Gillibrand, Donnelly, Warren, and Cortez Masto.

**OPENING STATEMENT OF SENATOR SUSAN M. COLLINS,  
CHAIRMAN**

The CHAIRMAN. This hearing will come to order.

Good morning. In 1983, the life expectancy of a person living with Down syndrome was just 25 years. As a result of advances in health care, a baby born with Down syndrome today can expect to live past 60 years, a dramatic increase in life span. To make the most of this progress, parents have been trying to ensure a secure future for their disabled children, and adults with disabilities have been working to enhance their own financial security. But that has proven challenging as poverty statistics demonstrate.

More than 56 million people in the United States live with a disability, and about 34 million of them are of working age, between 16 and 64. Last year this Committee examined issues such as educational and vocational training, and social and housing supports, that can help lead to a stable career and a more satisfying life for many people who have a disability.

It has not always been easy, however, for people with disabilities who can and want to work to save for their own futures. federal law caps the assets of a single person with disabilities who receives Supplemental Security Income, better known as SSI, at just \$2,000.

Depending on the specific disability, some individuals may require certain supports, ranging from help with basic daily activities to transportation and housing as they grow older.

Being able to save money to make necessary modifications to a car, or a home, or just to pay for unexpected life events, can preserve the independence of individuals with disabilities. And aging parents of disabled children should also feel secure about their children's futures as they enter into their own retirement years.

Today we will discuss policies that enable individuals with disabilities and their families to save, and thus achieve greater financial security as they grow older. Improving retirement security has been one of the major themes of the Aging Committee.

One such policy is the Stephen Beck, Jr. Achieving A Better Life Experience Act, also known as "The ABLE Act," which was authored by Senator Casey, the Ranking Member on this Committee and Senator Burr. It has shown promising results in states since it became law four years ago, and I want to applaud both Senator Casey and Senator Burr for their extraordinary leadership.

ABLE accounts have since been launched in more than 30 states. They allow individuals with a disability diagnosis by age 26, and their families, to establish tax-advantaged savings accounts. Similar to the 529 college savings plans, these savings accounts can be used to set aside contributions not to exceed \$15,000 a year to cover qualified expenses such as education, housing, and transportation.

Recently I met with members of the Autism Society of Maine who shared that Maine is on the verge of establishing its own ABLE program. I am happy to report that Bangor Savings Bank will kick off Maine's ABLE program with pilot accounts starting very soon. I know the Autism Society and many others in Maine are eager to see this program launched, and they welcome the opportunity for greater savings for disabled individuals and their families.

It is important to note that approximately 27 percent of Americans with disabilities live in poverty. That is the highest rate of any subgroup in the country. This statistic demonstrates why we must provide these individuals with more opportunities for financial freedom and stability, particularly during their older years. And it underscores why the ABLE Act is so important.

As we will hear today, parents of children with disabilities were once discouraged from saving for their children's future. This led to needless worry, sleepless nights, and a lack of financial security. Today, however, ABLE accounts offer a means to savings that can turn the tide. These options provide a sense of security to help produce a brighter future full of hope.

I am now delighted to turn to Ranking Member Casey, who suggested that we have this hearing, for his opening statement.

**OPENING STATEMENT OF SENATOR ROBERT P. CASEY, JR.,  
RANKING MEMBER**

Senator CASEY. Chairman Collins, thank you very much for holding this hearing. I want to thank you for making it possible, because we want to explore today the economic health of people with disabilities and, of course, their families as they age.

All American families worry about their economic future, especially as we grow older. For people with disabilities, finances, savings and income are of great concern.

In 2015 the National Disability Institute commissioned a study that indicated that people with disabilities were more than two and a half times as likely to have difficulty covering their expenses than those without disabilities. The same study found that people with disabilities were almost twice as likely to be unable to cover

a moderate-sized emergency expense compared with those without a disability.

There are many reasons why people with disabilities and their families are in an especially precarious financial circumstance. I think our witnesses will provide us with some of these details today.

I want to emphasize that as people with disabilities age and as their families age, their economic challenges may become worse. There are almost 750,000 people with intellectual and developmental disabilities over the age of 60 who are living with their families. In addition, almost a million families with parents over 60 years of age are supporting their adult sons or daughters who have an intellectual or developmental disability.

People with disabilities are less likely to be employed and much more likely to be underemployed; therefore, their earnings over time are less than the average citizen. And because their primary support person, usually a parent, has had to care for them, often quitting their jobs to do so, the family's income has been curtailed significantly.

With fewer opportunities to earn income and significant barriers and penalties when trying to save, people with disabilities and their families often are in difficult—and that is an understatement—difficult financial situations.

Congress has removed some of the barriers to savings in order to plan for the future. Senator Collins mentioned the work that Senator Burr and I did to pass the Stephen E. Beck Achieving a Better Life Experience, known as the ABLE Act, that passed with overwhelming bipartisan support in both Houses of Congress back in the latter part of December 2014. I want to thank Senator Burr for his work and for the work that was done in both Houses to get that done.

The ABLE Act makes it possible now for people with disabilities to save for future expenses, as Senator Collins mentioned, in a manner similar to a 529 college savings plan. They now can save for a variety of expenses whether it is education, health care, assistive technology, paying for a move, for example, to obtain a job—a whole range of expenses that are important to their lives. They can save for their future without losing their federal disability benefits such as Supplemental Social Security Income or Medicaid.

With the opening of ABLE accounts in now 39 states, over 21,000 people have been able to save what is now over \$105 million, an average of \$5,000. That \$5,000 is, of course, \$3,000 more than the limit prior to ABLE becoming a reality. And these families and these individuals can save up to \$100,000. Having assets means that people can open their own businesses, they can save for retirement, and they can purchase the technology that they need.

But we do need to do more. ABLE is not available to people who acquired their disability after their 26th birthday. There are still limits to monthly earnings that keep people with disabilities underemployed and not able to accept a promotion at work without losing their benefits.

As a Nation, we have begun to address these barriers to economic health for people with disabilities and their families as they age. I look forward to hearing more from our witnesses and learn-

ing what you think are the next steps that we should take to continue to help the 56 million Americans with a disability to be economically healthy.

Thank you, Madam Chair.

The CHAIRMAN. Thank you very much.

I see that we have been joined by both Senators from North Carolina, which shows their wisdom today, but I particularly want Senator Burr to know that I have been raving about the work that you did with Senator Casey on the ABLE Act. I am sure your staff can get you a transcript of the compliments.

Senator CASEY. You can add mine to that.

The CHAIRMAN. First I would like to introduce Dr. Kelly Nye-Lengerman—I hope I got that right—from the University of Minnesota’s Institute on Community Inclusion. Her work as an expert social worker for disability provider organizations in both community- and facility-based programs has enabled her to help many individuals with disabilities to achieve economic security.

I will now turn to Senator Burr, the co-author of the ABLE Act, to introduce our next witness, who is from his home state.

Senator BURR. Madam Chairman, thank you very much, and welcome. It is my pleasure to welcome Ben Wright from Wilmington, North Carolina. Ben is a small business owner, an advocate, and a proud parent of four children, two of which have Down syndrome. I want to thank the Committee leadership for inviting Ben to testify.

I also want to thank the Ranking Member, Senator Casey, for his work over the years in helping to lead our bipartisan effort to pass the ABLE Act and to improve upon the initial success of the ABLE Act.

Some have called the ABLE Act the “most significant piece of legislation affecting the disabled since passage of the Americans with Disabilities Act almost 30 years ago.” Senator Casey and I got involved in an effort to pass ABLE over 10 years ago. This has been one of the toughest pieces of legislation that made the most common sense of anything I have tackled in the time that I have been here. The amount of families around this country that are impacted, not just parents but grandparents and relatives, who can now have the comfort of knowing that a child that has a fruitful life in front of them also has the security of a nest egg to make sure that they have whatever they need, regardless of what they run into.

Ben and his wife, Amy, are truly incredible people, and I am lucky to have served them in the United States Senate. Ben and his wife started Beau’s Coffee Shop in 2016 to employ people with disabilities. I think I surprised Amy one day when I all of a sudden showed up in Beau’s Coffee Shop, no notice, only to order a smoothie. And today the coffee shop has grown to employ over 70 individuals and has been named “Bitty & Beau’s” after their two children.

Since opening, they have shown countless customers that all Americans are capable of working alongside each other. Just this past year, Ben’s wife, Amy, received the CNN Hero of the Year Award for her advocacy and continued efforts to improve the lives of others.



In addition to Bitty & Beau's, Ben is a financial planner where he helps families save for the future. Ben's financial planning business also employs a number of Americans with disabilities, and Ben currently serves on the board of the North Carolina ABLE Program. Ben continues to raise awareness of ABLE programs and educate families on the benefits of opening an account.

I think it is safe to say that the ABLE Act has begun to change the way we think of federal benefits for Americans with disabilities just as Ben and his wife have begun to change the way Americans view people with disabilities. Ben, welcome. Thank you for being here.

Thank you, Madam Chairman.

The CHAIRMAN. Thank you very much, Senator Burr, for your leadership.

Next I would like to introduce Edward Mitchell from Jackson, Tennessee. In 2003 Mr. Mitchell was the victim of a hit-and-run accident that left him paralyzed. He now lives independently with the help of a nurse and his parents. He is a strong and passionate advocate for people living with disabilities and works to educate others about the benefits of the ABLE accounts, which he himself is using.

I now will turn to the Ranking Member to introduce our witness from his state.

Senator CASEY. Thank you, Chairman Collins. And before I get to Jack Stollsteimer, I do want to say Mr. Mitchell gave me two of his cards today. One is paper, of course. This is especially neat. It is made out of metal, so I will pass it around. I think we should try these in the Senate. They are more durable cards.

But I am grateful to introduce Jack Stollsteimer. I have known Jack for a long, long time. I will not say he is an old friend. I will say he is a friend of long standing. That sounds a little better. But Jack is Deputy Treasurer of the Commonwealth of Pennsylvania. He resides—still in Havertown, Pennsylvania?

Mr. STOLLSTEIMER. Yes, sir.

Senator CASEY. His duties as Deputy Treasurer include the management of the 529 college savings program—programs, plural, I should say—and, of course, the Pennsylvania ABLE program. Jack was charged with planning for and implementing the Pennsylvania ABLE program and oversaw the opening of the program in April 2017. Through his leadership, the Pennsylvania ABLE program has been the fastest growing ABLE program in the country. The program is also one of the most heavily invested in the country, with the average account balance over \$6,000, more than \$1,000 higher than the national average.

In addition to his current duties, Jack has been a dedicated public servant in our Commonwealth, serving as one of the Assistant District Attorneys in Delaware County and then also the Assistant United States Attorney for the Eastern District of Pennsylvania. His current responsibilities in the Treasurer's office include consumer programs and public engagement.

Jack, thank you for being here today. Thanks for your testimony.

The CHAIRMAN. Senator Tillis, I know that Mr. Wright is your constituent as well, and I want to give you a few moments to make any comments.

Senator TILLIS. First, I want to welcome you all. It is good to see you again. I ordered coffee, by the way, Senator Burr, when I went to Bitty & Beau's. But I also ended up with some Facebook friends as a result of that visit, and I was paying attention to his opening comment, but I was taking a picture of you and your family to post it on Facebook, so hopefully some of my friends out there will see it. But thank you for the work. And I think really the coming together of the community, the facility that you are in, to make it work or help you make the numbers work. But when we were out there, we talked about what more we can do to really provide more opportunities for a lot of people who want to work. They want to work in part to make money. They want to work in part to have independence. But, boy, I tell you what, if you are having a down day and you can get down to North Carolina and visit Bitty & Beau's, I guarantee you the rest of your day is going to be fantastic. Just the joy and the optimism is palpable.

Thank you all for being here.

The CHAIRMAN. Thank you very much, and we will now start with our witnesses. Dr. Nye-Lengerman, we will have you go first.

**STATEMENT OF KELLY NYE-LENGERMAN, PH.D., MSW, UNIVERSITY OF MINNESOTA, INSTITUTE ON COMMUNITY INTEGRATION, RESEARCH AND TRAINING CENTER ON COMMUNITY LIVING, MINNEAPOLIS, MINNESOTA**

Dr. NYE-LENGERMAN. Good morning. Thank you, Chairman Collins, Ranking Member Casey, and members of the Special Committee on Aging, for the opportunity to speak with you today. My name is Kelly Nye-Lengerman, and I am a researcher at the University of Minnesota's Institute on Community Integration and Research and Training Center on Community Living.

Millions of individuals with disabilities and their families do not access the American Dream in the same way that others do. They do not have the same pathways to savings and to earnings.

First, people with disabilities are more likely to be unemployed, underemployed, and living in poverty. People with disabilities are more than twice as likely to live in poverty, and family units that include a member with a disability have average household incomes nearly 45 percent less than the average American household.

Second, the act of caregiving for a family member with a disability creates challenges to families that prevent them from having a regular income, accessing health care, or saving for the future. Caregiving duties range from simple to complex, such as helping someone go to the grocery store, transferring someone from a wheelchair to the tub for daily bathing, or administering complex interventions such as tube feeding or suctioning. These responsibilities often increase as the family member with a disability ages, and they become more difficult to perform as family members who are caregivers age. And estimates currently suggest that 25 percent of caregivers for adults with disabilities are over the age of 60.

And, third, as individuals with disabilities and their family members age, they can become more reliant on public support programs. Our current policies often require that individuals and families remain in poverty to maintain eligibility for these programs.

As an addendum to my written testimony, I incorporated four family profiles that included their perspectives on policies that support economic security for families, and I would like to use some of those family experiences to highlight some of the research findings from our center.

First, we found that without paid employment, people with disabilities do not retire nor have savings later in life. The majority of people with intellectual and developmental disabilities did not retire because they did not have paid employment. The Hofer-Van Ness and Rigotti families have high expectations for their adult children with disabilities to have a job, and more importantly, their children, Andy and Nick, want to work, too. Without the right supports, finding, securing, maintaining, and succeeding in a job have been incredibly difficult. Having a job and saving for their future ensures that Nick and Andy have more economic security.

Strong employment policies such as the Workforce Innovation and Opportunity Act improve public work force systems that support people with disabilities, including youth, to have a job and find a career. WIOA establishes competitive, integrated employment for people with disabilities as a clear national priority.

Our studies have also indicated that a family member who supports an individual with a disability has drastically reduced abilities to earn and save due to high caregiving demands. In one study in partnership with the Arc of the United States, we found that 90 percent of respondents reported that they had out-of-pocket expenses, and of that group, nearly 40 percent of families spent between \$5,000 and \$20,000 annually.

All four families explained that they had out-of-pocket expenses for their family member that included co-pays, medical supplies, paid support, and transportation. While they have been able to manage these expenses, these expenses can also represent a significant economic burden to families. Policies that support pathways to savings such as ABLE can potentially offset the burdens of out-of-pocket expenses. The ability to save without penalty or ineligibility for other support programs opens new doors for families to financially be able to provide more equitable footing from which to save in the future.

Additionally, access to paid leave is recognized as a critical component for being able to keep and maintain a job when complications of a disability or family member needs arise. Other benefits offered by employers such as flexible work schedules, health care, flexible spending accounts, and supportive supervisors have been identified as family caregivers as essential to help keep them working when a family member with a disability has needs.

Ms. Michele Hilgart shared an example of how her employer customized a position with her so that she could meet her son Ben's care needs, maintain her employment, and keep the family's health insurance coverage.

We also know through research that supporting people with disabilities to live in family homes or their own homes is significantly less costly to society. Institutional settings cost an average of \$128,000 annually compared to \$51,000 annually for care in family homes. Community settings save money, and most people with dis-

abilities and their families prefer to live and be a part of their community.

But we also found that family caregivers are in urgent need of relief and support. As family caregivers age, their need for respite care increases. In one study, 92 percent of families who use respite care reported that they were unable to find respite staff or providers. Three of the four families profiled have a family member living at home, and when asked, these families would not have it any other way. Their family member with a disability was an integral part of their family unit. Ms. Debbi Harris said, "We are not a family without Josh. And if we did not have him, we would be broken." Josh's care includes 24-hour skilled nursing, but is heavily supplemented by his mother, his father, his two brothers, his 58-year-old uncle, and his 85-year-old grandfather.

To keep people with disabilities in family homes or their own homes, a strong direct support work force is needed. Direct support professionals provide essential services to individuals with disabilities and their families so they can live, work, and participate in the community, as well as give family caregivers much needed respite. The direct support work force is one of the highest demand professions in the U.S. today and a lifeline for people with disabilities and their families.

In closing, I urge the Senate to include policies that address these three critical needs:

Continue to encourage savings and earnings, and ABLE is a great pathway to savings as it should be extended to people with disabilities beyond the age of 26 years of age, at the same time removing barriers to earnings that people with disabilities face, such as the substantial gainful activity limit.

Support the development and retention of a strong direct care work force, and without this work force, people with disabilities will not be able to earn and save for the future.

And, last, enhance our meager family support system and respite care. Without support, families earn less and multiple generations are financially fragile. We need a support system that makes it possible for families to earn and save for their future and the future of their family members with disabilities. Long-term investments in employment and caregiving make it possible for people with disabilities and their families to work, save, and plan for their older years.

Thank you most sincerely for the opportunity to share testimony today and your interest in this topic.

The CHAIRMAN. Thank you very much for your statement.  
Mr. Wright.

**STATEMENT OF BENJAMIN WRIGHT, FATHER AND BUSINESS OWNER, WILMINGTON, NORTH CAROLINA**

Mr. WRIGHT. Chairman Collins, Ranking Member Casey, distinguished members of this Committee, thank you for inviting me to testify this morning. It has been exciting over the past few years to witness the passing of the ABLE Act, the ABLE to Work Act, and the ABLE Financial Planning Act, spearheaded by Senators Burr and Casey. While there is still much work to be done, such as signing the TIME Act into law, I want to thank everyone on this

Committee for all that you have done and continue to do for people and families living with intellectual and developmental disabilities.

As the father of four children, I spend a lot of time thinking about their futures, especially what life might look like after high school for our two youngest children, Beau and Bitty, who have Down syndrome. As most of you know, it is estimated that over 70 percent of adults with I/DD are unemployed. That is a staggeringly high unemployment rate that should not be tolerated in this country. Imagine any other group where seven of ten people did not have jobs, and I think people might take to the streets. And yet in regards to this group of unemployed people, there is no outrage from the majority of the American citizenry, only bewilderment on the faces of those who endure this discrimination and hopelessness in the eyes of those who love and advocate for them.

It begs the question: Why the complacency? I believe what we are really dealing with is not a classic unemployment problem driven by the economy, but a bona fide social and cultural problem. Doesn't it seem that people with I/DD are not ascribed the same value in our society as those of us without disabilities? What other group of law-abiding citizens can be paid a sub-minimum wage just because of who they are?

And yet, paradoxically, before dinner tonight, every one of us in this room could acquire the equivalent of an intellectual or developmental disability due to an unforeseen event. And then what? Having a disability is nothing to be ashamed of; it is part of the human condition, so much so that the U.S. Census reports that one in five Americans has a disability. And yet, here we are—with an eye-popping 70-percent unemployment rate.

So what can we do? I believe if we can find ways to help people without I/DD see the intrinsic value in people with I/DD, accepting and including them should come more naturally.

My wife, Amy, and I have given this a lot of thought, so much so that two-and-a-half years ago, we decided to open a coffee shop called "Bitty & Beau's Coffee," where we employ almost 80 adults across three coffee shops and everyone earns above minimum wage. Initially, we thought this was a great way to reduce the unemployment rate. But what we quickly realized was that the real power of the coffee shop was its ability to show people without disabilities what is possible. The point of Bitty & Beau's Coffee is not that people with I/DD can work in coffee shops, but that people with and without disabilities could and should be working together, shoulder to shoulder, in almost every type of business.

People need a fresh perspective on this issue. They need to know and understand that people with I/DD are not broken. What is broken is the lens through which we view people with I/DD. And Bitty & Beau's is a new lens, and it is changing the way people see other people, offering a new perspective that, once seen, cannot be unseen.

If the goal of this hearing is to support economic stability and self-sufficiency as Americans and their families with disabilities age, efforts such as ABLE and addressing policies that inhibit work for people with disabilities are critically important. But we must also resolve to help people without disabilities see people with dis-

abilities, like my children, Beau and Bitty, as worthy of that charge.

Thank you for your time.

The CHAIRMAN. Thank you very much for your moving testimony. Mr. Mitchell.

**STATEMENT OF EDWARD MITCHELL, INDEPENDENT LIVING  
SPECIALIST, JACKSON, TENNESSEE**

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

Let me share a bit of background on myself. I have not always lived with a disability. My disability occurred on March 29, 2003, in Jackson, Tennessee. On that ill-fated day, my life was nearly destroyed when I decided to go for a bike ride with my little brother before going to my first high school job at Little Caesars under great owners, Kevin and Rachel Colbert. As I rode my bike, I noticed a fast-moving truck coming from the rear. After I gave my hand signals, I switched into the left-bound lane where my life was changed. A truck crossed over the double lines and clipped me from behind, throwing me into a ditch. I landed on my back and my neck, and it caused an incomplete fracture to my C5-C6 vertebrae.

From that point on, my life had taken a turn. I had become a victim of a hit-and-run that continues to remain unsolved. As it stands today, I get around with the use of a powered wheelchair. I do not have feelings in my legs—I do have feeling in my legs but no voluntary movement.

Since that time, I have graduated high school. I have attended Lane College on a full ride, graduating magna cum laude, and then went on to earn my MBA from Union University. I currently work with the Jackson Generals minor league baseball team going on four years, and I am also an independent living specialist at the Jackson Center for Independent Living.

As they say, it is hard to keep a determined individual down. But I still need nursing care assistance with my nighttime routine and getting up and getting ready for the next day. I also need assistance with home modifications as well as vehicle modifications. I need to try to figure out what I can do and what changes need to be done for my family to take care of me and assist me, especially as we all grow older.

One of the consequences of my accident is my father lost his job and had to dip into his savings. He used some of his 401(k) savings to help with expenses. He later took a job out-of-state just to keep my family in a stable environment.

Now, I know you are probably wondering why do I keep taking part-time jobs. I have been gaining experience. I have completed my master's, but I cannot accept a full salary for any significant amount of money because that would impact my nursing care benefits. If I accept a full salary, I will make too much and lose my disability benefits. But I would not make enough directly to pay for nursing care, even if I gave my whole salary to a nursing care agency.

When it comes to my support services, I am limited in nursing hours through my Medicaid waiver. My mother still assists me

with about 35 hours of support weekly. As demonstrated in these examples, living a life with a disability in many circumstances has inherent financial challenges and extra expenses that are typically not held by my able-bodied peers. Luckily I have been able to take advantage of one tool that has recently become available to individuals with disabilities, and that is to open an ABLE account.

On one of these evenings, my mother was up late winding herself down after helping me when she stumbled across the Tennessee ABLE program. ABLE accounts are bank accounts that allow people with special needs to save money without jeopardizing their disability benefits. ABLE accounts are from the ABLE (Achieving a Better Life Experience) Act, and they are established and managed on a state level.

Once we stumbled upon ABLE, I received support from the ABLE National Resource Center managed by the National Disability Institute. We realized that this was a lifeline. Money saved in a traditional bank account counts against the ability to qualify for disability benefits or Medicaid waiver programs.

As a result, individuals with special needs are not able to build savings with the money they earn or that they receive from an inheritance, gifts, or life insurance policies. This means individuals must live with very little money if they want to receive government aid or, as in my case, qualify for Medicaid waiver programs that pay for nursing care.

I have tried to put away a little bit from each check since opening my ABLE account. The ABLE program gives my parents peace of mind because they are aging. My parents want to make sure that I am able to take care of myself and be as independent as possible, because the biggest life expenditures I have are nursing care, housing, and especially wheelchair transportation, which is extremely astronomical in my case, also reaching up to \$100,000. The ABLE program helps with being self-sufficient.

That being said, ABLE accounts are only available to individuals with disabilities that encountered their disability before their 26th birthday. As I mentioned, my injury occurred when I was a teenager; therefore, I am allowed to open an ABLE savings account for my future. If something similar was to take place after I was 26, I would not have the ability to open and build for a financial future without having to forfeit my nursing care supports.

I know that Senator Casey has introduced the ABLE Adjustment Act which will begin to increase the age provision by law. I would strongly encourage the members of this Committee to support this piece of legislation. It would allow millions more individuals with special needs a chance to build a brighter economic future.

Additionally, I would like to make two more recommendations about making it possible for people with disabilities to economically be self-sufficient.

It is my wish that states will make it easier to transfer waiver programs. If you receive a waiver in states, it is not easy to transfer it to another state if you are looking to relocate or take another job.

My second recommendation would be for individuals like myself that are career-driven to have nursing care that we would pay into

a program which would be on a sliding scale, so as we could take different advancements, we would pay back into the system.

In closing, I want to be self-sufficient and continue to climb the corporate ladder. I never wanted to start receiving Social Security benefits, but my life changed in 2003. As my path of my life is leading, it may be into a career in politics, and with the help of ABLE and disability benefits, I might be able to achieve that because ABLE has been a lifeline. Thank you.

The CHAIRMAN. Thank you very much for your testimony and personal story.

Mr. Stollsteimer.

**STATEMENT OF JACK STOLLSTEIMER, DEPUTY STATE TREASURER FOR CONSUMER PROGRAMS, PENNSYLVANIA OFFICE OF THE STATE TREASURER, HARRISBURG, PENNSYLVANIA**

Mr. STOLLSTEIMER. Thank you, Chairman. Good morning, Chairman Collins, Ranking Member Casey, and other distinguished members of the Committee. I am Jack Stollsteimer, Deputy State Treasurer for Consumer Programs, and on behalf of Pennsylvania Treasurer Joseph Torsella, I am grateful for the opportunity to appear before you today to discuss our Department's ABLE program and how it is improving the lives of people with disabilities of all ages by helping them achieve economic self-sufficiency.

The PA ABLE program was launched by Treasurer Torsella in April 2017 after a bipartisan group of state legislators, supported by a broad coalition of advocates for the disability community, enacted strong enabling legislation in 2016. The Pennsylvania ABLE Act includes provisions exempting ABLE accounts from Medicaid paybacks and offering account holders protection from creditors in state legal proceedings.

Since the implementation of the PA ABLE Act, our Legislature has continued its strong support of the program by creating a state tax deduction for contributions to ABLE accounts and through an annual appropriation for Treasury to market and administer the program.

In the 15 months since our program launch, we have seen a surge of interest for the benefits offered by the ABLE program from people with disabilities of all ages. We have a number of account holders who are working adults with disabilities who find the freedom for the first time to hold significant funds in their own account without jeopardizing their access to federal disability benefits truly liberating. We have parents of young children with disabilities saving long term for their children's future by making small but regular contributions without paying the up-front fees required to open a special needs trust. We have older adults using ABLE funds to purchase adaptive technology to enable them to live more productive, fuller lives. And we even have parents of account owners using ABLE accounts as estate planning vehicles to ensure their children's future financial security. Currently our ABLE program has more than 1,400 account holders with \$8.3 million under management, and each of those account owners has their own story as to why ABLE is the best option for them to save, to pay bills, and to make debit card purchases through their ABLE account. We have made so much progress, but we have so much more work to



do. There are over 60,000 children with disabilities in Pennsylvania; with ongoing support from federal and state policymakers, our goal is to reach as many of them as we possibly can.

Over time the ABLE program can provide a means for people with disabilities to achieve greater self-sufficiency as they age as long as our federal partners continue to support the program's promise. The ABLE program works for people by allowing anyone with a qualifying disability a secure, tax-advantaged way to save or invest without impacting their government benefits. But it also works because the Internal Revenue Service has broadly interpreted the definition of a "Qualified Disability Expenses," thereby allowing people with disabilities the flexibility to use the program throughout their lives, since the nature of an individual's expenses change to reflect their different stages in life. Simply put, the qualified expense needs of a 25-year-old worker in many respects are very different from the expenses of a 65-year-old retiree.

Right now ABLE provides the flexibility to accommodate the changing needs of people as they age, but we must ensure that remains true in the years to come. And to that end, the Pennsylvania Treasury would strongly encourage the Senate to consider Senator Casey's bill, Senate bill 817, the ABLE Adjustment Act. This bill would greatly increase the utilization of the program by allowing individuals with disabilities that started before age 46 to open ABLE accounts. Increasing the number of people with disabilities who can open accounts will strengthen the ABLE program from a fiscal perspective while allowing older adults who become disabled through accidents, chronic illness, or military service to use this tool for their economic stability and self-sufficiency.

Senator, thank you very much for the opportunity.

The CHAIRMAN. Thank you for your testimony.

Since this hearing was requested by the Ranking Member, I am going to defer to him for his questions first.

Senator CASEY. Chairman Collins, thanks very much. And, again, thank you for holding this hearing.

I want to start by reiterating some of the comments I made in my opening about the work that Senator Burr did with me and our staffs over many years, not only to get ABLE passed but to continue to work together on several pieces of legislation to improve it. So I want to commend and salute him for his work, and I think I at least have to go to one coffee shop in North Carolina because he has made a fulsome recommendation today, so we are grateful for that opportunity.

I wanted to start with Deputy Treasurer Stollsteimer about the uptake in Pennsylvania, the number of accounts. We know that the dollar amount is higher than the average, and we are grateful for that. We have some 1,400 account owners in just 15 months in Pennsylvania. I wanted to ask you, Deputy Treasurer Stollsteimer, why you believe that is the case, why we are, at least in Pennsylvania, moving at a faster rate maybe than some other places.

Mr. STOLLSTEIMER. Senator, thank you for the question. I do not want to jinx ourselves. We are off to a good start, but the program has a long way to go, as you know.

I think our success so far has really—we could chalk it up to three factors.

One is the commitment Treasurer Torsella made to giving every resource Treasury has to make this program a success from the moment we took office.

The second factor, I think, is the support, the bipartisan support we have gotten from the Pennsylvania Legislature. Senator Baker from your area and Representative O'Neill have been stalwart supporters of the program, and the resources that we need at Treasury they have given us to market the program.

And the last thing, and probably most importantly, is the engagement we have been able to do with the disability community. What we have found is that we need validators in the community to tell people that this new program is something that is a benefit to them and that they should not fear. There is still a lot of fear in the disability community over losing their benefits by saving money in their own name, and we have to overcome that. And you may find this shocking, but people do not really want to take financial advice from Jack Stollsteimer. They need somebody in their life that they trust to tell them, yes, that program is trustworthy and you should get involved with it. And I think that is why we are successful thus far.

Senator CASEY. I want to reiterate what you said about the disability community. We could not have gotten ABLE passed nor could we pass improvements. Senator Burr and I were blessed to have that strong ally every step of the way.

I am also grateful to hear about the fact that it remains bipartisan at the state level. And, of course, the advertising, just like anything else in society, unless people know about it, we will not have people opening accounts. So we hope the General Assembly in Pennsylvania and in other states will continue to provide resources for advertising.

I wanted to next move to Mr. Mitchell. First of all, I commend you for not just being here today and your testimony, but also commend you for your achievements. You are accomplished by way of the degrees you have, a Bachelor of Science in business with a minor in marketing, and you also have an MBA, and we are grateful that you have worked so hard to do that, to achieve those degrees, but also the work you are doing in holding down two jobs and the work you do with others that have a disability.

I guess one of the things I wanted to amplify which you referred to in your oral testimony—your written testimony goes into more detail—about the limitations that you have, legal limitations by way of current policy where it is almost impossible for you to earn more than \$40,000. Tell us about that and some of the barriers you have.

Mr. MITCHELL. Thank you. Some of the limitations that I have with not being able to earn more than \$40,000 is with different waiver programs you have these restrictions in money, so you can only make, let us say, \$2,500 this month. Social Security has another limit. It is always an adjusting scale where it is, you know, am I in compliance with Social Security? Am I in compliance with the waiver program? And sometimes they do not all talk to each other. Many times, you know, at least once every three years, I have to prove to Social Security I am disabled. I went eight months without a Social Security check because they did not feel like I was

a disabled because, you know, of me being employed and the titles that I held.

Periodically I do attend National Black MBA conferences, and one of the issues that came up was if I accepted a salary of, let us say, \$65,000 or \$70,000, right now under my Medicaid waiver, it says just for 27 hours, that is \$53,000. So just because, you know, let us say I brought in \$70,000, subtract 53 from that, how do I continue to live? So I have almost been forced to stay within the guidelines of Social Security and the Medicaid waiver just so I do not put a financial burden, you know, on my parents because I did not have my trial work periods. I started working in high school before my accident and returned after my accident, and, you know, I continued to work in high school, and I used up my trial work periods. And now when I have finished my MBA, if I was to take a new job, I do not have those trial work periods to try to build a cushion to come back. So right now I am kind of playing how do I get ahead without falling behind.

Senator CASEY. I appreciate that. Thanks for pointing that out. Thank you, Madam Chair.

The CHAIRMAN. Thank you.

Mr. Stollsteimer, in the State of Maine, the poverty rate for working-age people with disabilities is 30.5 percent, and that is more than three times the poverty rate for the general population in the State of Maine. I know that the ABLE program has not been in effect that long, but do you have any information that would suggest that ABLE accounts are helping to lower that poverty rate among those living with disabilities?

Mr. STOLLSTEIMER. Yes, Senator, I think they are. Again, we find people from all age groups who are starting to use ABLE accounts for different purposes. It is one of the most flexible programs possible. A working person can use it to pay their daily expenses, to use a debit card feature, to have a checking account for the first time in their own name. So it is helping them financially, but it is also empowering them to be able to make debit card purchases.

We just on Monday found a family in Pennsylvania, just to give you an example, of working-age twin sisters, and they have muscular dystrophy. And they love music, and they want to teach music, and they were not able to do that. But they were able to save money in an ABLE account to be able to put a down payment on a vehicle that another government program is going to adapt for them using adaptive technology to get them out and enrich the community. They are going to teach children music, and they are going to enrich their own life experience by earning a living doing that.

I think this program is so flexible by allowing people both to invest long term and also to use it to pay daily expenses that it is the best vehicle to help the people you are talking about. It is a disgrace that people with disabilities live in poverty. But I think ABLE is a vehicle for them to get out of that.

The CHAIRMAN. Thank you.

Doctor, given the work that you have done with families, I am interested in your comments on what I call the "sandwich generation," and many others call it that as well, and that is individuals

who are both taking care of a child with a disability and an aging parent who also has become disabled.

How do you see the ABLE Act assisting those individuals in the very difficult role that they are playing as a caregiver? And what other needs should we be looking at for them?

Dr. NYE-LENGERMAN. Thank you for your question. I think the panel did a very nice job today talking about one of the key ingredients of ABLE is that flexibility. And for that group of compound caregivers that are sitting sort of in between a younger family member with a disability and an aging parent, what you need is more time, resources, and energy to be able to meet your own needs and your family member's needs, and what ABLE really does is a vehicle for that. So when you can use a debit card, when you do not have an overly burdensome paperwork process or a reimbursement process, it makes some of those life decisions that we may take advantage of being as part of our everyday practice, it makes it easier for families to live their lives the same ways that everybody else does.

And I think the other thing is you cannot underestimate the power of what peace of mind brings in reducing stress both on the physical and mental health side of that when you have, if you will, a space to save in a way without penalty, what that can bring both for your younger son or daughter with a disability or your older parent, that that can relieve some of those other burdens that we really have a hard time sort of figuring out how to best support families.

So I think, again, it is that flexibility piece and, again, making sure that families know that it is available to them from trusted sources, saying, yes, let us keep adding and investing to our ABLE accounts.

The CHAIRMAN. Thank you.

Mr. Mitchell, I was struck when you talked about your mother just stumbling onto the fact that ABLE accounts existed in your state. What more, aside from this hearing, which I hope will raise awareness, should we be doing to try to publicize the availability of these accounts?

Mr. MITCHELL. So far, what I think, you know, especially working as an independent living specialist, it is just publicizing it, getting it into vocational rehabilitation, possibly having somebody at the Social Security offices, also the independent living centers, just making sure everybody is on board to know exactly what ABLE accounts are, you know, what are the pros—you know, there are very few cons—because some just do not understand. Some people are scared away because you have so many misnomers out there, you know, about Medicaid recoupment. You know, they will take this. You know, people want to be in your business. And I am in a rural area. Jackson is the biggest city in between Memphis and Nashville, and some people are just scared, you know, by a new piece of legislation that they do not understand and very few people have.

So I try to get as much information as possible. I was recently selected to be a national spokesman for the ABLE accounts, so I just try to get out there. I try to educate the school system. Anybody I can talk to about ABLE, I try to do that because I try to

show them that this is a benefit, this is something new. And, you know, why not do it?

The CHAIRMAN. Thank you.

Senator Cortez Masto?

Senator CORTEZ MASTO. Thank you, Madam Chair and Ranking Member, for holding this hearing. And thank you to all of you for being here and having this conversation.

Mr. Mitchell, let me start with you. Let me just ask you this: I am from the State of Nevada, and there are almost 400,000 people with disabilities living in Nevada, and over half of them have some type of physical disability. In your position as an independent living specialist—and you work to keep people with disabilities in their own homes—what type of expenses would a person with a disability need to save to be able to continue living in their home or their apartment or with a parent or sibling? I think that is enlightening for people to know because I am struck by the fact that it is not just about getting the job and an income. I think people need to understand the additional expenses that are incurred and why you still need the support from Social Security or Medicaid or Medicare. So if you could talk a little bit about that, that would be helpful. Thank you.

Mr. MITCHELL. Yes, ma'am. There are many expenses that go into keeping someone independent and living in their home. For me, transportation, a wheelchair modified van is almost in excess of \$100,000 with electronic hand controls modifying it. Accessible bathrooms—an accessible bathroom, at least in rural West Tennessee, is almost \$12,000 for us to do just a generic one.

Wheelchair ramps, people think they last forever. But depending on the climate that you live in, dry rot, animals, things can deteriorate that, and, you know, a 40-foot ramp in West Tennessee is almost \$4,000.

Medical supplies—myself, you know, I get assistance from my mother and father, but I have catheter bags so I can use that on the go, different other leg bag extensions to make sure that I am able to stay proactive, going out with my peers. But these are things that are not covered by insurance. So you can ask—you know, supplies can run, for a 3-month supply it can be \$2,000 out of pocket. So if you can only earn \$2,000 a month, you know, under Social Security, where do you pull from? These are things that people get, you know, every year. It is hard for individuals with disabilities to stay in their home and especially those that are cold in nature, because they will run their heat higher at night.

So if they do not have, you know, transportation, a wheelchair ramp, the accessible bathrooms, and even more so if they need nursing care, it is hard for them to stay in the home. So that is why, you know, people stay under Social Security so then they are able to get those Medicaid waivers.

Senator CORTEZ MASTO. Thank you. I appreciate that.

Let me just say I have a cousin, a first cousin who I grew up with who is wheelchair-bound, has a disability, and my aunt takes care of him. And I will tell you, it was not until they were able to afford a van that accommodates my cousin being able to actually use his wheelchair to ride up into the van, it made them more mobile. Other than that, they could not get around. I think people

need to understand the additional costs that come and the burden on persons with disabilities or people with disabilities, that that is why these savings accounts are key, and that is why I support the ABLE adjustment account. I think we need to be doing more.

Mr. Wright, thank you. I think you are absolutely right, there is some sort of stigma. I do not understand why, but thank you for what you are doing, you and your wife. And I think we should be doing more of this, and this brings me to the next question I have. I am running out of time. But, Dr. Nye-Lengerman, you have looked carefully at the issue of employment and people with disabilities. In the State of Nevada, we actually have a relatively high work force participation rate for people with disabilities. It is, as of 2016, about 42 percent, and that is according to the University of New Hampshire.

You know, have you looked at this across the country and the rate of participation for the work force? And do you have any reason why Nevada's work force participation might be higher than others or other things that we can be doing in our states?

Dr. NYE-LENGERMAN. Yes, thank you for your question. One of the things that we find when we look at different types of uptakes, policies and services, sort of the data that comes from states, one of the strongest predictors of anything, whether it comes to work force participation, to where people are living, to how they are using their Medicaid dollars, is the state in which they reside. And so state context is an incredibly important factor in how services and systems play out for people with disabilities. And so there really are these economic features that occur within each State. There are sort of the cultural features within state agencies, maybe your state vocational rehabilitation program or your state intellectual and developmental disability organizations, like a Department of Human Services, and how they prioritize and invest in certain things. And we definitely see that there is a wide variation in how states choose to invest in funding and supporting employment for people with disabilities. And there really are really significant gaps.

And so my best guess for Nevada specifically without digging in a little bit of those numbers is that some of your state agencies, maybe some of your business partnerships, have really invested and zeroed in on these issues as a priority for that particular State. And what we often see as well, too, is that these sort of—again, I said cultural context of a state about what sort of brings that energy and attention to the issue as well can have a really big deal, and that has a lot to do with advocacy leaders, parent leaders in the State, as well as state leadership within state agencies and at the federal level as well.

So I think it is a really exciting and important finding to highlight, and I would be very interested in digging into that a little bit more. But thank you for sharing.

Senator CORTEZ MASTO. Thank you. I notice my time is up. Thank you all again.

The CHAIRMAN. Thank you.

Senator Tillis?

Senator TILLIS. Thank you, Chair Collins and Ranking Member Casey, for requesting the hearing.

Mr. Wright, I want to get to a question for Mr. Mitchell about some of the economic challenges, but I would like to talk about maybe some of the challenges that you all have faced as an employer and what more we can do to encourage other businesses to provide more workplace opportunities.

Mr. WRIGHT. Senator Tillis, thank you for the question. We have faced a number of challenges, and I think it revolves around just the misunderstanding of what it means for people with disabilities to work. A couple of ideas around that, you know, making ABLE accounts a little bit more accessible, too. I know everyone is doing their darnedest to make that happen, and marketing obviously, as in all things, helps.

But I wonder if maybe during early intervention services if ABLE accounts might be brought up to the families, at the least an information sheet, a one-pager, maybe automatic enrollment. I know there is some difficulty because every state—you know, lots of states have them, so how do you choose which one? But at least an information sheet.

Also, at IEP meetings, it might be brought up then, ABLE accounts, a single-pager right there.

And then, last, if you are lucky enough to find someone who will hire you, maybe you have an information sheet or auto enrollment again when you are filling out your W-2, where automatic enrollment, automatic direct deposit, away you go. There might be some really practical ways to increase the accessibility of the 529(a) accounts.

But, you know, specifically I really do think it is the business community that has got to step up largely, you know, and say there is this massive group of folks with disabilities who can work, who want to work. I think research shows that people with disabilities largely want jobs. So maybe incentivizing business owners to look at hiring people with I/DD. Are there some sensible tax credits that we could offer, some payroll tax holidays for some amount of time, something. Even SBA loans, might we work with the SBA to say, hey, look, if you as a business are committed to hiring some percentage of people with disabilities over the term of your loan, we will discount your interest rate by 25, 50, 100, 200 basis points, whatever it is, and monitor that using different agencies, or however you can put it all together.

But I really think incentivizing businesses is the key to this, because imagine if every small business in this country hired one person with a disability for competitive, inclusive employment, we would not have this unemployment problem.

Thank you, Senator.

Senator TILLIS. Thank you.

Mr. Mitchell, so much of what you said makes no sense in terms of providing a disincentive for you to continue to grow and build on your career. Have you given much thought to how we could figure out a way to kind of strike a balance? Because you look to me like somebody that could be making a seven-figure income if you wanted to go down that path versus a political career. By the way, I have got a brother who is in the Tennessee State Legislature, so if you all need some work over there, we should connect you two together. But, you know, some sort of a mechanism—clearly at

some point you could be a person of means who you could expect to defray some of the expenses so that we have the resources for those who can. Have you looked at that or have any opinion on that?

Mr. MITCHELL. Yes, sir. I would say something such as a sliding scale as to, let us say, when you hit plateaus, if you start earning \$45,000, you pay this much into your waiver program for nursing; you get a boost and you get to \$65,000, so I would think more of a sliding scale. So as that person climbs, you know, he climbs that corporate ladder, they are able to contribute back into the system, but eventually they will get to that income level to where they are able to buy a house, they have enough savings to say, hey, I have figured out a way to manage my nursing care, so I can come off this waiver program because now I have succeeded in climbing in whatever industry they try to get into and they are able to give back and let somebody else try to climb as well.

Senator TILLIS. And it seems to me there needs to be an incentive as you move up this scale, the incentive to continue to work, grow your income so that at some point perhaps you become financially independent. I think that is something we have to look more at.

Dr. Nye-Lengerman, I know states vary. You mentioned that in a prior comment. Are there states that we should be looking at as particularly best practices or better practices, some that stand out as where we would like most of the other states to be as a norm?

Dr. NYE-LENGERMAN. Well, I have some interesting states that are maybe unique. One of those states is the State of Washington that produces some of the best employment rates for people with disabilities. Now, that was really a part of a really meaningful and purposeful shift on the part of their state intellectual and developmental disabilities agency to say we are no longer going to be using public funds through Medicaid to directly pay for segregated or sheltered work. And so it is sort of saying we are going to close the doors and try to create those spaces in our communities where people with disabilities can work, and that was a really important step. But in policy, as we know, we always have these unintended consequences.

So one of the things that we see, for example, in the State of Washington is that you do see higher rates of people with disabilities working in competitive integrated employment. But you also see—and I have heard it referred to as sort of reverse segregation in the sense of whereas people might have been going to programs and services during the course of a day, they are now in their own homes alone not working. So while they may be working 5, 10, 20 hours in the community, previously they were 30 hours in a day program or employment program with people, and now they may be at home more often than not.

So I think it is sort of the right mix of incentives for people to work, but also to have spaces to be a part of their community. So if they are not working, how do we make sure that people with disabilities are seen as valued and contributing members of society—which they are—to say work is important but also having support is important? So Washington is an interesting state.



Then there are some other states, the State of Ohio, for example, has really invested and really wrapped around this idea of employment first, of competitive integrated employment as being the priority for people with disabilities and the expectation. And so they really have allowed a number of their state agencies to sort of work to that end about how do we get VR and our Departments of Health and Education and Human Services to work together to that goal.

So those are two that kind of stand out that you sort of see get a lot of attention at the moment.

Senator TILLIS. Well, thank you.

Madam Chair, I have to go to a Judiciary Committee hearing after this, but, Mr. Wright, we would love to see you and your family in our office today. We are in the same building, down on the first floor, so we would love to see you if you have time later on. And thank you all for being here for this very important topic.

The CHAIRMAN. Thank you, Senator.

Senator Warren?

Senator WARREN. Thank you, Madam Chair. And once again, thank you for holding this hearing.

There are a lot of things we need to do to improve the economic security of older Americans with disabilities, and my colleagues have touched on a lot of them already: removing barriers to employment, making it easier to save, safeguarding health care coverage.

I want to talk about another very important program, one that helps seniors and people with disabilities, who have very low income and almost no assets. The Supplemental Security Income program, or SSI, it is a part of Social Security. In order to be eligible for benefits, a recipient has to have a severe disability or be over the age of 65, cannot have more than \$2,000 in total assets. That is counting your bank account, your life insurance, stocks, money under the mattress, everything. And for these seniors and people with disabilities who have very low amounts of assets and very little income, SSI provides an average benefit of about \$550 a month.

Now, Mr. Mitchell, I understand you work with people who receive SSI and that you receive it yourself. I know there are a lot of ways that we can improve this program, and I want to talk about those. But before we do, I would just like you, if you would, to say a word about the kinds of things you use those SSI payments for.

Mr. MITCHELL. Yes, ma'am. I use my SSI payments to defer costs such as wheelchair repairs, because there are, you know, so many miscellaneous things that come up, from a flat tire to a malfunctioning joystick. Also, you know, there will be other supplies such as, you know, I use suppositories, different things like that, because these are all things that fall in gray areas, and there are so many gray things—I mean things that fall in gray areas that you need to be able to contribute to and have the money to do so.

Just recently, you know, I had a consumer, he broke his wheelchair charger. It was 9 o'clock at night. We had to make sure that we found a way through JSCIL in order to make sure that he got a wheelchair charger.

So I use my SSI benefits for that, and I know other individuals and consumers I work with use theirs to cover those necessities, because there are just some things, you know, that you cannot get.

Senator WARREN. Good. I really appreciate your just explaining that to people, and I also want to say thank you for your incredible work that you do for people with disabilities in Tennessee. It really is remarkable work.

What worries me is that rather than strengthening this important program, the White House has proposed billions of dollars in cuts to SSI, breaking President Trump's promise not to cut Social Security. Instead of cutting this crucial lifeline for low-income seniors and people with disabilities, we should be doing everything we can to improve this program.

The ABLE Act is an important step toward allowing SSI recipients to buildup their savings, and I am very grateful for the leadership from Senator Burr and Ranking Member Casey and other members of this Committee that worked on this issue. But there are also other ways that we could also improve SSI itself.

So, Dr. Nye-Lengerman, you are an expert on poverty and disability as well as on employment for people with disabilities. Could you tell us about how SSI's limits on recipients' income and assets affect their ability to buildup any financial security?

Dr. NYE-LENGERMAN. Thank you for the question, Senator Warren. I would be happy to explain that.

In a nutshell, SSI, the Supplemental Security Income program, looks at a number of things. They first look at SGA, which is called "substantial gainful activity," and what that does is it basically says this is the amount of money that is OK to have in earned income over the course of a month. For a non-blind individual—they use the binary blind or non-blind—that SGA is \$1,180. For an individual who is blind, that limit is \$1,970. So anytime you go over that SGA in that month, it reduces your monthly benefit.

And so what we see is this sort of disincentive, if you will, to work in the sense that you may be able to have a part-time job and earn \$2,000 a month. But if you do, your Social Security is going to go down.

Now, there are some other incentives, and we talked about trial work periods, really that are helpful, but that is one of sort of the sticking points that makes it hard because people are afraid when you count on something like SSI like that. But the other component is the asset limit that you referenced as well. For an individual that asset limit is \$2,000, and for a couple that is \$3,000. And so, again, it really is difficult—really impossible to move out of or beyond poverty because of those limits.

Senator WARREN. So people have both a disincentive to work, have to live right on the edge of poverty. Can you tell me when those numbers were last updated?

Dr. NYE-LENGERMAN. They were last updated in 1989, and they have only been updated I think three times since the program rolled out in the 1970's.

Senator WARREN. Right. In fact, I understand some of the numbers have never been updated since 1972.

Dr. NYE-LENGERMAN. That is correct.

Senator WARREN. So that is where we are holding people. You know, these outdated asset and income limits are barriers that prevent SSI recipients from building a better future for themselves and for their families.

I am glad to be a cosponsor of Senator Brown's SSI Restoration Act which would allow recipients to save up for emergencies, to earn a little more money for work and other sources without being penalized, and to receive support like food or shelter from friends and family members. These changes will help ensure that the SSI program fulfills its promise and better serves those who need it most.

Growing old or having a disability should not mean struggling to put food on the table or worrying about keeping a roof over your head. We should be a better country than that, and we should make sure these programs live up to our values.

Thank you, Madam Chair.

The CHAIRMAN. Senator Burr, you have been extremely patient in listening through a lot of testimony and questions. I again want to applaud you for your leadership and working with Senator Casey in authoring a law, the ABLE Act, which is really making a difference for so many families across this country.

Senator BURR. Well, Madam Chairman, let me thank you for two things this morning. One is this is the longest period uninterrupted I have had in 6 months.

[Laughter.]

Senator BURR. Actually being in here, and I think the fact that you were doing this, the intelligence staff knew to stay away. They only came one time.

But it has also given us an opportunity to highlight the success of ABLE, and let me just requote some numbers. In the first three months of this year, 2018, the number of accounts has grown 19 percent; the amount of invested assets, 37 percent; and the average account size grew 15 percent. In the past year, the number of accounts grew 177 percent; the invested assets, 290 percent. All that in the last year. And I think Senator Warren hits on a very important thing. Isn't it time for us to update everything?

I remember when Bob and I started this—what, 10 years ago? And, you know, it sort of gets bent at the question that stumped you. Why doesn't everybody that is disabled have an ABLE account? You know, that is mystifying. We created it, we built it, it is there. And the fact is that things do not happen overnight. It requires maybe incentivizing employers, educating the disabled, convincing states—thank you for what Pennsylvania has done—convincing states to set the accounts up.

When Bob and I started in this, it was with the greatest detail to flexibility. It was with an appetite that was every bit as big as everybody has expressed up here, but with the reality that we could only do certain things and get it accomplished, and we had to pick and choose what was the most important. And I think to some degree with the cooperation of the disabled community, we have been masterful—and the support of our colleagues—that we have not tried to bite too big a bite of the apple, and had we, America was not ready for it. American business was not ready to employ them. States were not ready to set up accounts.

You know, I am not sure that the average person who is disabled, Mr. Mitchell, and would like to have an ABLE account understands that if they live in Tennessee, they can set their ABLE account up in North Carolina. Since 2016, that ability has existed. So if there is a state out there that does not have one or you do not like the people, come to North Carolina. Set your account up. We have made it as easy to participate as we possibly can. Now we are getting to the tough part. How do you expand it? And how do you expand it at rates that exceed—probably if we had said could you grow it 190 percent in a year's time, we would have said no way. But we started with a very low bar.

And, Ben, I have got this question for you. What do you think are some of the reasons that individuals who qualify for ABLE accounts do not set them up?

Mr. WRIGHT. Senator Burr, thanks for your comments and the question. I think quite simply they are just not aware of them. I think it is as simple as that. I know that there are a lot of folks out there trying to get the word out, but, you know, marketing is expensive. It takes some bucks to get the word out, whether it is social media, whether it is printed materials, word of mouth. I know in our own State of North Carolina, folks go out to different groups and give speeches. Well, that is great for the people who are in attendance, but those who are not do not hear it, right?

So that is the main reason, and that is why I go back to that notion of perhaps when people fill out a W-2, they are filling out an ABLE account form at the same time, and then back it up all the way to early intervention services, because families will start talking about it.

Then I think it also goes back to Mr. Mitchell's—I think it was your comment about they are afraid they are going to lose those supports, you know? People say, "No, you are not," but they are so afraid of it that they do not—it is almost like they do not even want to read it. So we have got to get people over that and really make it more ubiquitous. And maybe it is, again, that piece of paper in front of them when they are signing that W-2 or what have you.

Senator BURR. Is there more the disability community can do—and I am not talking about the disabled; I am talking about the advocacy groups that are out there. Are they selling to people that they have their e-mail addresses, they have their mailing addresses, they have monthly contact with these individuals, are they selling ABLE like they should?

Mr. WRIGHT. That is a great question. I do not know the answer to that, so I might defer to somebody who has those statistics or knowledge.

Mr. STOLLSTEIMER. Senator, I can tell you from Pennsylvania's perspective, you are exactly right. Ignorance of the program is the first hurdle, and then fear is the second part. People are terrified they are going to lose their federal benefits if they sign up for this program. And it is not enough for Treasury to tell them that this is a safe product. We have a customer service staff who go out and make presentations. But we need disability organizations, advocacy groups to start answering some of those questions for us.

Just the other day I got a call from the Arc in my own home county who had misinformation about what qualifies or is not a qualified expense. And so they are going to call a meeting of their members to have our staff come and explain to them in detail. And it is a one-on-one kind of a thing. We really do need to engage with individual families about this.

And then there is the whole financial literacy piece, right? You have to be able to understand whether you want to be an aggressive investor or a moderate investor or whether you want to do the debit card feature and the checking feature.

So it is relatively easy. You could sign up online. But there is all this fear that we still have to get over.

Going back to the ignorance for a minute, we have been in the college savings business, thanks to Congress under the 529 section of the IRS Code, for 25 years in Pennsylvania. Nationally only a third of people know about the 529 programs. So we have been at this for 25 to 30 years, and we still have to be able to break through to the families and let them know that this great vehicle exists for them.

It is going to take a long time for ABLE, but it has to be done, sir, it has to be engagement with the advocacy groups, or it is not going to succeed.

Senator BURR. Mr. Mitchell?

Mr. MITCHELL. Yes, sir, Senator Burr. I work for the Center for Independent Living in Jackson, Tennessee, and we try to push out ABLE to our consumers that come through the doors. But I think it needs to be a three-pronged attack.

I think, one, we need to get the school system involved. As parents get their kids in school, those counselors that know that somebody is on an IEP or they have a disability, give them the literature there.

But also the rehab facilities such as the Shepherd Center or the Shriners Center, Le Bonheur, getting their social workers on board, because if you can get the parents early or if there should be an accident, they realize that this vehicle is out there.

And, third, I would say also getting with NCIL, which will be here in Washington next week, getting with that advocacy group, and the independent living centers throughout the states to really help push ABLE and show them that—you know, show them success stories. That is one of the reasons why I was chosen as an ABLE national spokesman to really get the word out. But the more people we get signed up sharing their success stories—you can be like, “Oh, I know Paul. Paul down the street has an ABLE account. I can go there.” Or at school, you may have a counselor that will say, “Hey, remember Mr. Mitchell graduated 5 years back? He is still in town. Let us contact him. He has been successful with ABLE.”

So I think it is just a multi-tier attack that we need to get it, not only from the disability side but also from the school system side.

Senator BURR. Mr. Mitchell, thank you.

Chairman, you have been generous with time. Let me just say I think we have learned a lot today. We have learned that the majority of those with disabilities really want to work, but for decades,

for some of them, they have been penalized to do it. And now we are beginning to change that stigma, and we need to look at things that create a comfort on their part to work and to contribute to ABLE. It is amazing to me that a high school counselor—every student graduating knows about the student loan program, but every disabled student in that school probably is not told about an ABLE account. I think there are simple things. This is not different for us to do.

I am not going to speak for Senator Casey, but I think he would probably agree with this statement. When I leave this institution and I am asked, “What was the most important legislation you did in your congressional career?” I do not think there is any question. In my case it would be the ABLE Act. It is not the biggest, it is not the sexiest, it does not affect the most people. But it affects the folks that have the least amount of voice, and it is the community that really can be benefited for life in what we do.

I thank the Chair.

The CHAIRMAN. Again, thank you for your leadership.

Senator Gillibrand, so glad you could join us.

Senator GILLIBRAND. Thank you, Madam Chairwoman and Mr. Ranking Member. I am really grateful we are having a hearing on how we can talk about economic stability and self-sufficiency for Americans with disabilities, and I am very grateful for the leadership Senators on this Committee have shown in not only putting the ABLE Act in place but having a hearing to talk about its successes.

I want to talk about the area that it does not cover and offer three ideas for you guys to think about as experts on this issue.

We know that the ABLE Act does not cover you if your disability accrues after the age of 26. We also know that the parents of people who are disabled are not eligible to have these savings accounts included as well. And we know that because, as Senator Burr said, we have to make certain decisions about what to cover and what to do quickly. So I have three ideas I would like your thoughts on, and particularly Kelly Nye-Lengerman, since you are an expert on poverty and disability.

So the first idea is really simple: having a national paid leave plan. We are the only industrialized country in the world that does not have national paid leave, and most people do not have access to it. Only about 15 percent of all workers have access to paid leave. And you know as caregivers, if you do not have time out to take care of the people in your family when they need it most, it really disadvantages you or your ability to earn long term, to be able to go in and out of the work force quickly, not lose your spot at the job you have. Typically for caregivers they have to start over on the bottom rung if there is a family emergency. And we also know that a lot of our caregivers are aging; 860,000 caregivers are over the age of 60 nationwide and are providing care for some of the disability. So it is really important that we think about paid leave as a way to meet some of the needs that are not being met.

I do not know if you have any expertise on this, but you did mention it in your opening comments. Would you like to say anything about it?

Dr. NYE-LENGERMAN. I would, and I think one of the positive things about having a strong paid leave program nationally is that it meets and can serve both caregivers and people with disabilities. And so on the caregiving side, if a family member needs to step away to provide some type of support or care for a family member, they can, like you said, not losing their employment or spot in line, if you will. But it also is beneficial to people with disabilities because there are issues related to health and disability that come up. They come up for all of us. They may come up differently for people with disabilities. And so having a paid leave plan really provides that opportunity and safety net so people can stay in the work force, because also what we are talking about today is it is not just about savings, it is also about earnings. And so paid leave for both people with and without disabilities and caregivers is very important.

I would also say to your comment about making sure of ABLE's accessibility to other groups or other populations, a number of panelists—and I think we have talked today about increasing that age when an individual acquires their disability is another pathway that seems to make a lot of sense.

Senator GILLIBRAND. The second idea, and this is something Senator Burr talked about, he said people want to work, and I thought that quote was really important. And I think people with disabilities desperately want to work. But so few who are disabled have access to employment and access to basic training. In fact, the statistics say that the rate for persons with a disability of unemployment is 9.2 percent for 2017. That is double the national rate. So declaring victory at four-percent is not so great if you happen to be disabled because you are at 9 percent.

So my question is: What is your thinking about moving us toward this notion that anybody who wants to be working full-time should be able to have access to the training they need to get that opportunity and really put the investment behind this goal of full employment, this goal of actually getting us to a place where training is guaranteed? Is that something that—and all of you could talk about this issue—you would be willing to think about and maybe testify about? Edward, if you want to go first?

Mr. MITCHELL. Actually, that falls in line with vocational rehabilitation. Vocational rehabilitation, I can only speak from Tennessee's part, they try to live that philosophy. But they need to embrace it a little bit more because people you want to say work, and there is nothing wrong with any job, but people want gainful employment.

Senator GILLIBRAND. Right.

Mr. MITCHELL. You do not want to be held back folding towels. When I went through my brief—I was a former dean of students, an academic monitor at a college. I went through a brief spell of unemployment and got back involved with vocational rehabilitation. And some of the jobs that they were suggesting were not demeaning by any means, but you have to have the job—you know, what their counselors are looking for, you need to make sure that the job fits the individual, and not taking away anything, just some jobs that they were proposing just was like more of a step back.

Senator GILLIBRAND. Right. You want to earn at your fullest potential.

Mr. MITCHELL. Yes, ma'am. And also vocational rehabilitation really needs to put, you know, I hate to say, their money where their mouth is. They want you to be employed—with me right now I am battling not having a vehicle. I got one vehicle modification back in 2008, but that vehicle has not lasted 10 years. I put over \$30,000 in repairs, and now it is a battle to get them to approve a second modification. And without a vehicle, how do I stay gainfully employed at both my jobs?

Senator GILLIBRAND. Right. The last issue, if Madam Chairman does not mind me raising it, is this issue of access to banking, because a lot of our disabled families and individuals do not have access to banking. In fact, if you are a head of household, your likelihood of being unbanked or underbanked is—18.4 percent are unbanked and 28 percent are underbanked. That is a huge number of people who do not have access to banking.

So one idea to address that is this idea of postal banking because we have so many post offices in every part of the country, we have 30,000 locations. For a rural state like Maine, it could be game-changing. For places around the country where they do not have access to banks because they just do not earn enough money. People who are disabled tend to be low-income earners and do not have enough money to meet any thresholds.

So I would love your thoughts, and you could do it in writing if you want, but, Kelly, if you want to give your off-the-cuff thoughts about whether access to banking would be important to the disability community.

Dr. NYE-LENGERMAN. Again, thank you for the question. I do feel a little stumped, so I will come back in a couple weeks with some thoughts on that. But it is very interesting because if you think about what supports people to access all kinds of different benefits, accessibility is one of those huge components. And, again, the post office is a very interesting way to think about it because you are, like, yes, there are a lot—

Senator GILLIBRAND. Well, they used to be able to provide banking and did it for a very long time, decades and decades. So it is for specific groups of people who have a certain earning level, but just having access so you do not have to rely on the payday lenders and other types of services that tend to be very predatory on poor people. I think it would be overwhelmingly helpful for the disability community.

So for all these issues, to the extent you want to think about it, I would be grateful if you would submit letters to the Committee on your thoughts of these three ideas as ways to meet the needs that are not covered by the ABLE Act. Thank you.

Thank you, Madam Chairwoman.

The CHAIRMAN. Thank you very much.

I want to thank all of our witnesses today not only for appearing here and your testimony, but for the very important work that you are doing in your communities and states. It really makes a huge difference.

As Chairman of this Committee, one of my top priorities has been to improve the financial security of all older Americans, in-



cluding those with disabilities. Today's hearing builds on previous work of our Committee. We have focused specifically today on the unique challenges of attaining and maintaining financial security for individuals aging with disabilities and for their family caregivers who are also growing older.

While those with disabilities have the same rights as everyone else, the data show that as a group they consistently face disproportionate challenges in employment, housing, and transportation, which makes it difficult for them to achieve financial security. That is why I am so excited about the ABLE Act. We are beginning to make progress. ABLE accounts have already proven promising in nearly 40 states, and I cannot wait for Maine to launch its own program, which will happen very soon. I think we will be the 40th State. And I know we can count on Pennsylvania to give us any tips that are needed.

Senator Burr is right that Mainers can go to other states to set up the accounts, but it is a lot easier for people to do it in their own State. So I am looking forward to the day when we have all 50 states providing that service.

In addition to the ABLE Act, the RAISE Family Caregivers Act, which was recently signed into law, will establish a National Family Caregiving Strategy to guide our efforts moving forward and I think can make real contributions in this area in enabling individuals with disabilities and their families to save and invest in their own future, improving their retirement security, also giving caregivers some respite, which so many of them could use.

I want to turn to Senator Casey for his final words.

Senator CASEY. Chairman Collins, thank you again for holding this hearing. I want to thank you for the work that went into planning this hearing and obviously our witnesses for their testimony.

Senator Burr, it is always great to be working with you on these issues, and thank you for taking so much time. We are glad you got a little bit of a break from the Intel Committee and that important work that you do there.

I think we have heard some great stories today about individuals with disabilities and their families and their efforts to plan for the future and how we can encourage others to improve their financial health. We know we have specific recommendations, including passing the ABLE Age Adjustment Act, and we will be working to do that. And Senator Burr and I have been working on a number of bills to improve and strengthen ABLE.

I would also, Madam Chair, ask unanimous consent to submit some testimony for the record from Pennsylvanians about the ABLE Act, if we could do that for the record.

The CHAIRMAN. Without objection.

Senator CASEY. Thank you very much, and I will quote from one of them. Elizabeth Bechtel from Boalsburg, Pennsylvania, right in the middle of our state, she said, "The ABLE program is proving its worth every day, allowing people with disabilities to build for a future that offers stability of services, a safety net for protection against catastrophic expenses, and the possibility of saving for a dream they might otherwise never be able to afford."

I think her words summarize how important this legislation is, and we are grateful that we have the opportunity to talk about it today.

Again, I want to thank our Chair, and I want to thank the advocates who are in the room. I see Sara Weir, a great advocate who helped us in those days leading up to the passage of ABLE back in 2014, and I am grateful for all the work of the disability community and those advocates who are with us today and who I know will be with us on the road into the future.

Thank you, Madam Chair.

Senator BURR. Madam Chairman?

The CHAIRMAN. Senator Burr.

Senator BURR. Could I also mention that last night the Virginia529 announced a partnership with the Capital Group, which is going to get at the heart of some of the—this is the first time we are seeing people put their money into marketing, and not to say Pennsylvania has not, but this is huge, and hopefully this will be an impetus that will get others out there competing for the available accounts.

The CHAIRMAN. Thank you for that addition. And as always, I want to recognize Senator Cortez Masto for her streak in participating in every hearing and always offering such insightful comments and questions. So thank you for being here. And I want to thank our staff for their hard work.

Committee members will have until Friday, July 27th, to submit any additional questions for the record. Again, my thanks to our witnesses. This concludes the hearing.

[Whereupon, at 11:08 a.m., the Committee was adjourned.]

---

---

## **APPENDIX**

---

---



---

---

**Prepared Witness Statements and  
Questions for the Record**

---

---



UNIVERSITY OF MINNESOTA

Testimony to the United States Senate Committee on Aging  
Economic Security and Health as People with Disabilities and Their Families Age  
July 18, 2018

Kelly Nye-Lengerman, Ph.D., MSW  
University of Minnesota  
Institute on Community Integration  
Research and Training Center on Community Living

Good morning. Thank you, Chairman Collins, Ranking Member Casey, and other members of the Senate Committee on Aging, for the opportunity to speak with you today about economic security and well-being for people with disabilities and their families. I am grateful to serve as a witness and share with you some of our research and provide information on the economic situation many people with disabilities and their families face as they age.

My name is Kelly Nye-Lengerman, and I am a researcher at the University of Minnesota's Institute on Community Integration (ICI), Research and Training Center on Community Living. ICI is Minnesota's designated University Center for Excellence in Developmental Disabilities (UCEDD). We are a research, training, and outreach center focusing on disability policy and services across the lifespan. A number of our current and past research projects have examined employment, economic outcomes, and well-being for people with disabilities and their families and caregivers.

Economic well-being includes a broad range of social, emotional, and health factors that extend well beyond how much money an individual or family has earned or saved. Millions of individuals with disabilities and their families are not able to access the American dream in the same way others do, as they do not have the same pathways to earning and saving. There are a number of significant obstacles they face, and cumulatively over a lifetime, these barriers make economic security later in life more challenging.

First, people with disabilities are more likely to be unemployed, underemployed, and living in poverty. "Disability is a cause of poverty as it is associated with job loss, reduced earnings, restricted opportunities to save or invest money, workforce entry barriers, and more limited access to education and jobs. Disability can also be a consequence of poverty because poverty limits access to healthcare, education, and jobs, or restrict the ability to save, all of which can adversely affect health and economic wellbeing necessary supports" (Vallas, Fremstad, & Ekman, 2015). People with disabilities are more than twice as likely to live in poverty compared to people without disabilities (27 percent vs. 11 percent), and people with cognitive disabilities, which include intellectual and developmental disabilities (IDD), are three times more likely (32 percent) to experience poverty (Erickson, Lee, & von Schrader, 2017). The labor force participation rate is the percentage of the population that is working or actively looking for work, and as of June 2018 was 33% for working-age people with disabilities compared to 78% of people without disabilities (Brennan-Curry, 2018). This employment gap between people with and without disabilities remains fairly consistent over time. Kraus et al. (2018) report that thirty-four states have an employment gap of 40 percentage points or greater, and only three states showed an employment percentage gap less than 23 percent.

Second, the act of caregiving for a family member with a disability creates many challenges to families that prevent them from having a regular income, accessing healthcare, or saving income for the future. An estimated 25 percent of American families include a member with a disability between the ages of 18-64, and that number rises to 43 percent of households include a member over the age of 65 with a disability. Nearly 40 million family members provide care for loved ones with a disability (Coughlin, 2010; Reinhard, Feinberg, & Choula, 2015). Caregiving duties range from simple to complex activities: such as assisting someone to go to the grocery store, physically transferring someone from a wheelchair to the tub for daily



bathing or administering complex interventions such as tube feeding or suctioning. These responsibilities often increase as the family member with a disability ages and these support activities become harder to perform for family caregivers who are also aging.

The majority of caregiving provided by families is unpaid and not reimbursed through insurance or public support programs. In 2013, U.S. families provided an estimated 37 billion hours of care for people with disabilities of all ages, children, and older adults worth an estimated \$470 billion (Reinhard et al, 2015). Many Americans over the age of 50 are what is sometimes referred to as “compound caregivers,” which means that they are providing care to a family member with a disability and an aging parent or relative simultaneously. Compound caregiving leaves little time for caregivers to take care of themselves and, as a result, these caregivers experience higher rates of stress, depression, and other physical and mental health issues from which there is often little reprieve (Perkins & Haley, 2010). This adds to challenges with being able to work, earn a living and save.

Family units that include a member with a disability are also more likely to live in poverty. The average household income for a family with a member who has a disability is nearly 45 percent less (\$43,300 annually) than the average household income of a family without a member who has a disability (\$68,700 annually; Erickson et al., 2017). In addition, households in which there is a member with a disability which have an income of \$59,000 or less have reported higher negative social, emotional, and economic impacts of caregiving (Anderson et al., 2018). In sum, individuals with disabilities and their families have fewer economic resources in general than the average American family.

Third, as individuals with disabilities and their family members age, they can become more reliant on public support programs such as Medicaid, Medicare, Supplemental Nutrition Assistance Program (SNAP) and/or Supplemental Security Income (SSI). With life expectancies increasing for people with and without disabilities and the changing demographics of the workforce (i.e. worker to retiree ratio), the demands and needs for these supports have never been higher.

Adding to this complexity, many public support programs inadvertently keep individuals and families in poverty in order to maintain eligibility. Two examples include: substantial gainful activity (SGA) limits earnings over \$1,180 for non-blind individuals (\$1,970 for blind individuals) for some support programs like SSI, and the \$2,000 asset the limit for eligibility for other support programs like Medicaid. Support programs are critical lifelines for individuals and families but do little to assist in lifting them out of poverty long-term.

Collectively, these circumstances leave people with disabilities and their families in a difficult situation, having to make no-win decisions. An aging parent may ask, “Do I take early retirement to stay home with my son to provide care?” An adult with a disability may think, “I want to work but I’m not sure how taking this job might affect my healthcare benefits.” In our research at the Institute on Community Integration, we’ve tried to better understand the experiences of family caregivers and people with disabilities in order to inform practice and policy solutions. The following findings include a small sample of work by various researchers





at our center about out of pocket expenses, living environments, workforce challenges, respite needs, and retirement for people with intellectual and developmental disabilities (IDD).

**Finding 1. Without paid employment, people with disabilities do not retire, nor have savings for later in life.** One study we have conducted examines retirement for people with IDD. This research revealed that most people in this group are not actually retiring because they have not participated in paid employment over the course of their adulthood. Instead there is significant increase in facility-based, not community-based, day services as individuals with IDD age (Stancliffe et al., 2018). For people the few people with IDD who did retire, their entry into retirement was not gradual over time, as is typical of the general aging population, but instead is sudden, working one day and fully retired the next day. In the general aging population, people often decrease the number of hours they work each week as they age, gradually engaging in retirement. The pattern of sudden retirement for people with IDD, however, is characterized by an age-related decline in the percent of people working, without a marked age-related change in hours of work for those who remain employed. In this research, there was a segment of people with IDD who participate in paid employment that work well beyond age 65, which is also true for the general aging population. While we still know very little about retirement for older adults with disabilities, these findings highlight the fact that people with disabilities are less likely to be working and, therefore, likely have little to no savings from earnings, which limits their ability to retire in the same way that people without disabilities retire. With secured funding, our future research seeks to analyze other national data sets, including the Health and Retirement Study, and to examine healthy retirement planning and strategies for people with disabilities.

**Finding 2. Families with a member with a disability have a drastically reduced ability to earn income and save due to high caregiving demands.** Caregiving affects opportunities for economic mobility for both people with disabilities and their family members. We recently conducted a study, in partnership with The Arc of the United States, of family caregivers who provide support to individuals with intellectual and developmental disabilities. We found that 90 percent of respondents reported annual out of pocket expenses related to caregiving. Twenty percent reported having out of pocket expenses ranging from \$5,001-20,000 each year, and 17 percent reported spending more than \$20,000 in out of pocket expenses each year. Another study found the average annual medical expenses for a family that included a person with a disability were 300 percent higher than for families without a member with a disability (Altman et al., 1999). When most Americans, disability or not, only have savings of about \$500 to \$5,000, out-of-pocket expenses related to a disability can be financially devastating.

Solutions for this situation come not only from public support programs, but employers and businesses play a role too. Benefits offered by employers such as paid time off, flexible work schedules, healthcare, employee assistance programs, flexible spending accounts, and supportive supervisors have been identified by family caregivers as essential to help keep them working while caring for a loved one with disabilities.

**Finding 3. Supporting people with disabilities to live in family homes or their own homes is significantly less costly to society than housing them in group or institutional facilities.** Where a person lives can provide insight to caregiving capacity and needs. Today,



more than any other time in history, people with disabilities are living in the community, most often in a family home. Data from our Residential Information Systems Project (RISP), which annually reports on Medicaid Long Term Services and Support (LTSS) data for people with IDD reveals that most of these individuals are living with their families and require both formal and informal caregiving. In 2014, of the nearly 1.4 million people with IDD who were served by state IDD agencies, 57 percent lived in the home of a family member, 11 percent lived in a home they owned or leased, and 5 percent lived in a host home or with a foster family (Larson et al., 2017).

While there is a narrative that suggests “group housing,” or keeping people with disabilities together in one home, can save costs and reduce family caregiving, our research has found the opposite to be true. Living in the community in family- or self-owned homes is less expensive than institutional or nursing home settings. Institutional settings for adults with IDD cost an average of \$128,251 annually, compared to \$50,705 annually for care in family homes. The same is true for children with disabilities, with institutional settings costing \$118,540 annually versus \$18,531 annually for services provided in the family home (Larson et al., 2017). Community settings save money for both Medicaid and tax payers. We also know that, when asked, most people with disabilities and their family members prefer to live in and be a part of the community, which includes being part of their family in their home. Current estimates suggest that 25 percent of family caregivers in these homes are over the age of 60 (Heller & Factor, 2004). Given the vast majority of people with IDD live with aging caregivers, it is critical that Congress find ways to support family caregivers.

**Finding 4. Family caregivers are in urgent need of relief and support.** Families report that respite care provides them with much needed relief and space to attend to life’s other issues. Respite care is temporary planned or emergency care provided to care caregiver. As family caregivers age, the desire for respite care to balance caregiving and personal needs increases. Our Family Individual Needs Study (FINDS), in partnership with The Arc of the United States, found that over half of families used respite, and of that group 92 percent reported they had trouble finding respite care staff of providers (Anderson et al., 2018). Families rely on the direct support workforce to fill respite and other care needs. Interestingly, 50 percent of respondents in this study were caregivers between 50-64, 15 percent ages 65-74, two percent and were over the age of 75.

The current direct support workforce shortage, which include respite care, nationally has surpassed a crisis point. A series of recommendations on how to address this crisis is outlined in our recent publication: *Report to the President 2017 America’s Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy* (Hewitt et al., 2018). Selected recommendations include: providing sufficient funds for Direct Support Professional (DSP) wages and compensation packages in Medicaid rate-setting methodologies; providing technical assistance and financial or programmatic incentives to states to promote the use of technology solutions to create efficiencies; reduce costs and support community living; expand utilization of self-direction so that family, friends, and neighbors can be hired as DSPs; and investing in nationally recognized specialized credentials and professional development opportunities for DSPs. The implementation of these recommendations (and others from the report) are essential to stabilize the direct support workforce and provide aging family



caregivers relief and support so that a family member with a disability may continue to live at home or in their own home.

Key take-away messages from the body of research on the economic well-being of people with disabilities and their families include:

- Invest in and support employment for people with disabilities so that they can earn and save for the future. Current investments in employment for youth with disabilities today can lead to increased saving and decreased governmental support program expenses in the future.
- Support growth in flexible saving options, like ABLE accounts, to create safe spaces for families and individuals with disabilities to save funds without endangering eligibility in important support programs.
- Support family caregivers so they can stay in the workforce, maintaining access to healthcare, benefits, and retirement savings through their employers.
- Support and invest in a stable and competent direct support workforce to supplement family caregiving.
- Incentivize and support people with disabilities and their families in integrated community settings (i.e., their family home or their own home).

These issues represent tremendously complex policy and system challenges. However, there are a number of policy pathways and investments that can increase the economic well-being of individuals and families by supporting saving for retirement in older ages, helping people with disabilities stay in their own home, and bolstering assistance for aging family caregivers. Congressional action has provided the formative foundation for many programs which have benefited people with disabilities and their family caregivers. The Institute on Community Integration's research, policy advocacy, and engagement work inform the following recommendations:

**1. Support pathways to savings for individuals with disabilities and their families.**

The Achieving a Better Life Experience Act (ABLE) of 2014 led to the creation of ABLE accounts which are now held by more than 21,000 beneficiaries in the U.S. (Strategic Insights, 2018). These tax-advantaged savings accounts for individuals and their families recognize the extra costs of living with a disability. Various ABLE programs through STABLE, the National ABLE Alliance, and others represent nationwide access for families. With annual contributions of up to \$15,000, the beneficiary of the account (i.e., the person with a disability) is the account owner, which represents an important shift. The first \$100,000 in an ABLE account is exempted from the Supplemental Security Income (SSI) resource limit. ABLE accounts, although not yet widely adopted by families and individuals, are a tool for a significant, positive shift in economic well-being of people with disabilities and their family caregivers. The ability to save without penalty or ineligibility for other support programs opens new doors for individuals and families financially and provides a more equitable footing from which to save for the future, while potentially reducing the need for public support programs in years to come. Increasing the age of eligibility to those acquiring their disability before the age of 46 (from the current age of 26) would be welcome, along with additional investments to support family education about these accounts in order to increase enrollment and utilization. Growth of ABLE can be achieved through building trust with beneficiaries and their families through face-to-face interactions;



eliminating barriers to accessing ABLÉ; and making information about ABLÉ more accessible to families and beneficiaries from economically, linguistically, and culturally diverse communities.

**2. Keep employment policies and investments for workers with disabilities strong.**

The Workforce Innovation and Opportunity Act (WIOA) is landmark legislation that is designed to strengthen and improve our nation's public workforce system and help get Americans, including youth and people with significant barriers to employment, into high-quality jobs and careers, while helping employers hire and retain skilled workers. WIOA further establishes competitive, integrated employment for people with disabilities as a clear national priority, built on the goal of economic self-sufficiency. Opening WIOA regulations under a recent notification issuing a Notice of Proposed Rulemaking (34 CFR part 361) has the potential to undermine implementation. Additionally, Promoting Readiness of Minors in Supplemental Security Income (PROMISE) grants highlight a joint national demonstration effort between the Social Security Administration and the U.S. Departments of Education, Health and Human Services, and Labor, with a goal of improving employment and educational trajectories of youth with disabilities. The research focus of PROMISE is examining various interventions with youth and families to support post-secondary education and employment. Lessons learned and findings from PROMISE may illuminate promising ways forward that will increase employment and education, while decreasing participation on other support programs.

**3. A strong direct support workforce provides essential services to individuals with disabilities and their families.** The direct support workforce is one of the highest in-demand professions in the U.S. The direct support workforce provides essential services to people with disabilities so they can live, work, and participate in the community, while also providing much-needed respite for family caregivers. Solutions to the direct support workforce challenges are complex, but one important way to address the current workforce crisis is through the expansion self-direction in long-term services and supports (LTSS) so that family, friends, and neighbors can be hired as Direct Support Professionals. Paying family members for caregiving can relieve economic burdens on a family and can be a particularly helpful option to older family members who are entering their retirement years.

**4. Family caregivers and employed people with disabilities benefit from time off and support from employers.** Access to paid leave is recognized as a critical component of being able to keep and maintain a job when complications of a disability or family member needs arise. Despite the presence of the Family Medical Leave Act (FMLA), an estimated 40 percent of all Americans cannot access this benefit because they work for small employers, lack longevity in a job, or have not worked enough hours (Jorgensen & Appelbaum, 2014; National Partnership for Woman and Families, 2013). FMLA could be significantly strengthened through legislation, eligibility requirements, or employer participation to accommodate the needs of individuals with disabilities and their families so that they can retain their employment and stay in the workforce despite the demands of caring for a family member with a disability.



In closing, I would like acknowledge the research of my University of Minnesota colleagues whose research was cited today: Drs. Amy Hewitt, Sheryl Larson, Sandra Pettingell, and Roger Stancliffe, and Ms. Lynda Anderson. Funding from numerous federal agencies including the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration on Community Living (ACL), and others make research our possible.

As an addendum to my testimony, I have provided the committee with four family profiles that include their perspectives on policies that support economic security for people with disabilities and family caregivers. I hope you will take a moment to read recommendations from the Rigotti, Harris, Hilgart, and Hofer-VaNess families. Policies that make it possible for people with disabilities to work, save, and plan for their older years have long-term benefits that make it possible for us all to do better. Thank you again most sincerely for the opportunity to provide testimony and for your interest in this topic. I am happy to answer any questions the committee may have or provide additional resources.

Respectfully submitted by,

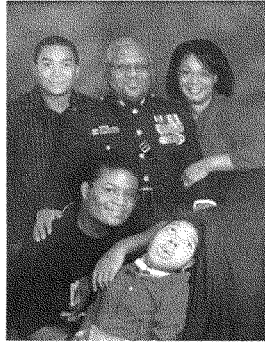
Kelly Nye-Lengerman, Ph.D., MSW  
Research Associate  
University of Minnesota  
Institute on Community Integration  
Research & Training Center on Community Living



### Nye-Lengerman Testimony Supplement

#### Family Experiences and Thoughts: Improving economic security for people with disabilities and their families

In preparation for my testimony, I reached out to four families who provide support to their family member with a disability. Most of these family caregivers are over the age of 50 and have concerns about what their family member's life as they age.



**Meet the Harris family.** Josh (26), Debbi (60), Victor (69), Nicholas (28), and Jonathan (31). Victor served in the U.S. Marine Corp., CWO-4, for 33 years and was deployed multiple times in his military career. Debbi has provided full-time care for Josh in their home for almost his entire life. She left the workforce at age 38 to protect and preserve Josh's quality of life. Josh requires 24-hour nursing care. While Josh has access to skilled nursing services covered through Tricare, private insurance, and Medicaid, his family members work regular around-the-clock shifts to support Josh and fill gaps in coverage. In addition to Debbi, Victor, Nicholas' shift, Josh's 85-year-old grandfather and 58-year-old uncle work weekly shifts providing care as well. Josh's oldest brother, who has a family of his own, comes home every other weekend to provide care for Josh during overnight shifts. Josh's other brother lives with Josh, Debbi, and Victor in the family home and also supports Josh throughout the week. Josh's care and support is a family affair and, though difficult, they have made it work. Debbi says, "We're not a family without Josh, and if we didn't have him we'd be broken." Their suggestions for reducing caregiving challenges and economic burdens include:

- Competitive pay for in-home nurses (as they don't earn as much as nurses in other medical settings) so that families can keep consistent, high-quality staff. Good staff help keep Josh alive.
- Invest in the workforce development (i.e., competitive wages, benefits, incentives, professional status, etc.) of nurses and direct support workers so they stay in the field. The lack of a consistent workforce puts the lives of people with disabilities at risk and increases family stress exponentially.
- Close loopholes in Tricare that make getting skilled nursing services covered. Hoop jumping, excessive paperwork, and lack of payment to nursing providers leads to unnecessary stress and trauma for families.
- Allow Reservists who are called to active duty without permanent change of station orders to be able to immediately access nursing or homecare benefits for their family member in order to prevent hardship for other families in the future.



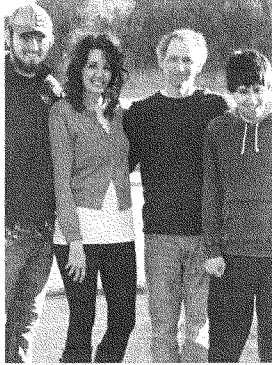


**Meet the Hofer-VaNess family.** Andy (29), Brian (67), and Jody (63). Andy is a young man, who, when properly supported, lives, contributes, and thrives within his local community. He also lives with an intellectual disability. As a family, this has not come without a cost. Andy's family has worked together to create both long- and short-term support plans for Andy later in life, and as his parents age. Whereas his family feels fortunate to have the services that support Andy in reaching his goals, his care has required one family member to forego the workforce to manage his services and provide critical transportation across his lifespan. Flexible tax credits for all income brackets for out-of-pocket costs associated with supporting a family member with a disability would have made a

significant difference in the economic and emotional well-being of his family. Today, as they move toward a new system of supports based on Andy's individual wishes, they find their family has had to have an ongoing financial commitment in the process. Thinking outside the current social service delivery box, with a focus on a community living, supporting Andy's goals can be a win/win for all. For his goals to be fully realized, however, and for the family supported in moving forward, certain funding mechanisms are required. As an adult, Andy's transportation, as well as wages and benefits that are commensurate with a job, are critical in his achieving fiscal independence, thus, allowing him to rely less on public support programs. Andy's family has also experienced tremendous gains by nurturing natural supports that already exist in places Andy wants to belong to help him engage and work in his local community. This has allowed his family to share his support needs with a greater community while decreasing the burden on government to provide paid care. Andy's family has worked tirelessly to find and nurture people of like mind, but not all families have this capacity. Funds are needed to support community training and a shift in culture and understanding around the role individuals with disabilities play in the world. So much more can be accomplished and money saved with a person-centered approach, but families need more flexible funding and options that support community integration. Andy's family is pleased and hopeful that you are addressing these disparities. In their experience, some of the greatest areas of growth and promise are:

- Individualized budgeting and consumer-directed supports through Home and Community Based Services (waivers) should be expanded.
- Information about ABLE accounts should be accessible to all family types in various economic circumstances. Some state-level rules regarding ABLE accounts can be overly burdensome.
- Investment priority should be given to public programs and services that promote and provide incentives for competitive, integrated employment. Providers are often not sufficiently motivated to shift their services to support employment in the community. Rather, more public funds are available for segregated services. We have struggled to find quality providers and staff to support Andy in community employment.
- Sub-minimum wage for people with disabilities should be eliminated. Everyone has a right to earn a fair wage.



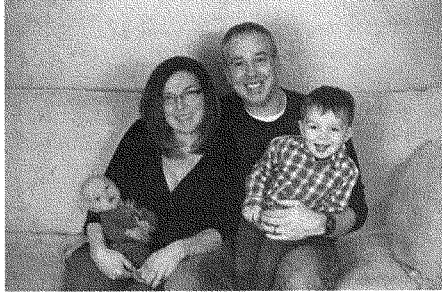


**Meet the Rigotti family.** Nick (23), Joe (21), Cindy (51), and Mark (55). Mark and Cindy are both small business owners in rural Minnesota. They are also both over the age of 50 and actively involved in their community. Nick lives at home, and they are happy he is there. It's where Nick wants to be too. Since he was young, Mark and Cindy always expected that Nick would work in the community. They spent years working with multiple school districts to provide Nick with the experiences he needed to join the workforce. Several years post-graduation, the Rigotti's are still struggling to find the right job supports for Nick. Staff turnover in Vocational Rehabilitation and in provider agencies has created discontinuities in service which have compromised Nick's success on the job. As a result of Nick's experience, Cindy started her own non-profit that provides work experiences to youth with disabilities, which has been extremely well received in her community. Mark and Cindy identified a few areas where the right policies could benefit Nick and their family's economic well-being as they, and Nick get older; they suggest:

- Improved, coordinated long-term job supports that would assist people with disabilities, like Nick, in finding and maintaining a job in the community, earning his own wages. The supports they received under WIOA from Vocational Rehabilitation and employment service providers could be greatly improved with quality, well-trained staff direct support staff who are consistent. Nick wants to work!
- Public and on-demand transportation in rural areas is non-existent. The Rigotti's and their extended family have spent hours driving Nick into the city for work experiences, appointments, and activities. Nick is capable of using public transit as he did so successfully when he was in school in a larger city but they simply do not exist where he lives now. Investment in public transit infrastructure would be helpful to them and reduce the significant costs they've invested private transportation.
- The Rigotti's save money for Nick's future but would like more saving opportunities. SSI limits what Nick can earn and save. They have used multiple different strategies to save for Nick, despite Nick not being the direct beneficiary of the account to safeguard some types of benefits. They would like other families have access to information and outreach about saving for future care needs for their child or family member. They are looking into an ABLE account in the future.







**Meet the Hilgart family.** Ben (6 months), Jackson (3), Michele (39), and Andy (39). The Hilgart's are an active and busy family. There are play dates, family gatherings, and lots of appointments. Ben was born with Down Syndrome. After his birth this February, he and his mother both met their out-of-pocket maximums in before the end of the month. Ben is benefiting from birth-to-three early intervention services and is already making progress! The Hilgart's pay \$200 per month for early intervention

supports. Michele had to go back to work after twelve weeks to maintain family insurance coverage, but her employer provided her with a customized position so she could meet Ben's care needs and maintain employment. In her newly created position, she works full-time from home, with 50 percent of her weekly hours (20 hours per week) fulfilled at any time, day or night. This benefit has allowed Michele to stay in the workforce, keep her insurance, and provide care to Ben. They currently have a 529 account for their son Jackson and will soon open an ABLER account for Ben. As a family new to the disability community they suggest:

- Access to high-quality early intervention services for all eligible children and families. Ben made measurable progress in just two weeks.
- Healthcare access is important for all people. Out-of-pocket expenses have to be manageable for families in different types of circumstances.
- Ensure information about ABLER accounts are available to all different types of families, are easy to understand, and aren't overly burdensome to maintain with excessive paperwork requirements.



### References and Resources

- Altman, B. M., & Blackwell, D. L. (2014). Disability in U.S. households, 2000–2010: Findings from the National Health Interview Survey. *Family Relations*, 63, 20–38.
- Altman, B. M., Cooper, P. F., & Cunningham, P.J. (1999). The case of disability in the family: Impact on health care utilization and expenditures for nondisabled members. *Milbank Quarterly*, 77, 39-75.
- Anderson, L, Hewitt, A., Pettingell, S., Lulinski, A., Taylor, M., & Reagan, J. (2018) Family and Individual Needs for Disability Supports (v.2) Community Report 2017. Minnesota: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. Full report found at: [https://www.thearc.org/file/documents\\_finds/FINDS\\_report-2017-FINAL-VERSION.pdf](https://www.thearc.org/file/documents_finds/FINDS_report-2017-FINAL-VERSION.pdf)
- Anderson, L.L., Larson, S.A., Kardell, Y., Taylor, B., Hallas-Muchow, L., Eschenbacher, H.J., Hewitt, A.S, Sowers, M, & Bourne, M.L. (2016). Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Full report found at: <https://fisp.umn.edu/>
- Brennan-Curry, A. (2018). nTIDE June 2018 Jobs Report: Modest Downturn in Jobs Ends Extended Run for Americans with Disabilities. Retrieved from: <https://researchondisability.org/epm-rtc/epm-news/2018/07/06/ntide-june-2018-jobs-report-modest-downturn-in-jobs-ends-extended-run-for-americans-with-disabilities>
- Coughlin, J. (2010). *Estimating the impact of caregiving and employment on well-being*. Center for Health Research, Healthways, Incorporated.
- Erickson, W., Lee, C., von Schrader, S. (2017). Disability Statistics from the American Community Survey (ACS). Ithaca, NY: Cornell University Yang-Tan Institute (YTI). Retrieved from Cornell University Disability Statistics website: [www.disabilitystatistics.org](http://www.disabilitystatistics.org)
- Family Caregiving Alliance. (2016). Caregiver statistics: Work and caregiving. Retrieved from: <https://www.caregiver.org/caregiver-statistics-work-and-caregiving>
- Family Caregiving Alliance. (2016). Caregiver health. Retrieved from: <https://www.caregiver.org/caregiver-health>
- Fujiura, G. T. (2014). The political arithmetic of disability and the American family: A demographic perspective. *Family Relations*, 63(1), 7-19.
- Gaugler, J., & Kane, R. L. (Eds.). (2015). *Family caregiving in the new normal*. Academic Press.



- Heller, T., Gibbons, H. M., & Fisher, D. (2015). Caregiving and family support interventions: Crossing networks of aging and developmental disabilities. *Intellectual and developmental disabilities*, 53(5), 329-345.
- Heller, T., & Factor, A. (2004). Older adults with Developmental Disabilities and their Aging family caregivers. *Chicago Research and Training Center on Aging with Developmental Disabilities*, University of Illinois at Chicago.
- Hewitt, A., Lakin, C., Macbeth, J., Kramme, J., & Benway, C. (2017). *President's Committee for People with Intellectual Disabilities Report to the President 2017: America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy*. Washington D.C.: President's Committee for People with Intellectual Disabilities. Retrieved from: [https://www.acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report\\_0.PDF](https://www.acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF)
- Jorgensen, H., & Appelbaum, E. (2014). *Expanding Federal Family and Medical Leave Coverage: Who Benefits from Changes in Eligibility Requirements?* (No. 2014-02). Center for Economic and Policy Research (CEPR).
- Kraus, L., Lauer, E., Coleman, R., and Houtenville, A. (2018). 2017 Disability Statistics Annual Report. Durham, NH: University of New Hampshire.
- Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2017). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Full report found at: <https://risp.umn.edu/>
- Mitra, S., Findley, P. A., & Sambamoorthi, U. (2009). Health care expenditures of living with a disability: total expenditures, out-of-pocket expenses, and burden, 1996 to 2004. *Archives of physical medicine and rehabilitation*, 90(9), 1532-1540.
- National Alliance for Caregiving (NAC) and AARP Public Policy Institute (2015). Caregiving in the U.S. 2015 – Focused Look at Caregivers of Adults Age 50+. Retrieved from: [https://www.caregiving.org/wpcontent/uploads/2015/05/2015CaregivingintheUSCare-Recipients-Over-50\\_WEB.pdf](https://www.caregiving.org/wpcontent/uploads/2015/05/2015CaregivingintheUSCare-Recipients-Over-50_WEB.pdf)
- National Partnership for Women and Families. (2013). A Look at the U.S. Department of Labor's 2012 Family and Medical Leave Act Employee and Worksite Surveys. Retrieved from: <http://www.nationalpartnership.org/research-library/work-family/fmla/dol-fmla-survey-key-findings-2012.pdf>



- Nord, D., & Nye-Lengerman, K. (2015). Employment for people with disabilities in poverty: A need for national attention. *Policy Research Brief*, 25(1), Minneapolis, MN: Research and Training Center on Community Living at the University of Minnesota.
- Nye-Lengerman, K. & Hewitt, A. (Ed.) (In Press). *A Community Life: Community Living and Participation for Individuals with Intellectual and Developmental Disabilities*. Washington, DC: Association of Intellectual and Developmental Disabilities.
- Nye-Lengerman, K., & Nord, D. (2016). Changing the message: Employment as a means out of poverty. *Journal of Vocational Rehabilitation*, 44(3), 243–247.
- Park, J., Turnbull, A. P., & Turnbull III, H. R. (2002). Impacts of poverty on quality of life in families of children with disabilities. *Exceptional children*, 68(2), 151-170.
- Perkins, E. A., & Haley, W. E. (2010). Compound caregiving: when lifelong caregivers undertake additional caregiving roles. *Rehabilitation Psychology*, 55(4), 409–17.
- Reinhard, S. C., Feinberg, L. F., Choula, R., & Houser, A. (2015). Valuing the invaluable: 2015 update. *Insight on the Issues*, 104.
- Strategic Insights. (2018). National comparison of ABLE Plans: 1Q 2018 Quarterly Update. Retrieved from: [www.sionline.org](http://www.sionline.org).
- Stancliffe, R., Kramme, J., & Nye-Lengerman K. (In Press). Retirement trajectories for individuals with intellectual and developmental disabilities. *Intellectual Disabilities*.
- Vallas, R., Fremstad, S., & Ekman, L. (2015). Center for American Progress: A Fair Shot for Workers with Disabilities. Retrieved from: <https://www.americanprogress.org/issues/poverty/reports/2015/01/28/105520/a-fair-shot-for-workers-with-disabilities/>



**Questions for the Record Submitted to Dr. Kelly Nye-Lengerman  
From Senator Jones**

**Question:**

Dr. Nye-Lengerman, in your testimony you also note that ABLE accounts have not yet been widely adopted, despite their many benefits. **Based on your respective expertise, what recommendations do you have for growing the ABLE program nationwide and increasing the accessibility of these accounts?**

**Nye-Lengerman Response:**

The passage of the ABLE Act represents a significant shift in promoting the economic security and well-being for people with disabilities and their families. Never before have people with disabilities been able to save meaningful amounts of money of their own accord without significant barriers. ABLÉ accounts play an important role in the economic self-sufficiency for people with disabilities in the years to come. To strengthen and expand ABLÉ the following could be considered:

- Continue to encourage savings and earnings. ABLÉ is a great pathway to savings and it should be extended to people with disabilities beyond 26 years of age. At the same time, remove the barriers to earnings that people with disabilities face, such as the substantial gainful activity (SGA) limits and asset limits within Social Security and Medicaid.
- Develop federal guidelines for professional management and standards of practice for ABLÉ account management, similar to 529 programs, to prevent predatory practices, unethical marketing, and excessive fees. Without strong federal oversight, populations vulnerable to exploitation could be put at additional risks.
- Develop and deploy cross federal agency marketing to diverse populations and communities. Using the vast network of public programs such as Social Security, Medicaid, public education, create media tools to inform individuals and families about ABLÉ. Examples could include: ABLÉ materials as part of a vocational rehabilitation (VR) or Medicaid applications, part of individualized educational planning (IEP) or 504 planning under IDEA, each of which are touchpoints where people with disabilities come in contact with the larger federal and or state support services. A national ad campaign could also be beneficial. Additionally, providing materials on ABLÉ in languages others than English would be valuable, with attention being given on how to best communicate with diverse and marginalized communities.
- Explore or invest in national demonstration research on savings matching for developing ABLÉ accounts for high needs populations, such as those receiving Supplemental Security Income (SSI). For example, SSI recipients may benefit from benefit stabilization windows during saving, having fewer reductions in SSI payments if dollars are being saved in an ABLÉ account, or matching dollars up to a percentage placed into an ABLÉ account as a benefit offset; the goal being to study the effects and impact of savings (i.e. ABLÉ accounts) of high needs, high cost populations.
- Encourage and support ABLÉ account programs to invest in partnerships to disseminate information about ABLÉ (i.e. possible grants or pilot projects). Individuals and families are less likely to enroll in ABLÉ if information is not shared by a trusted source or ally known to the person or family. Partnerships with schools' districts, parent information centers, advocacy organizations, workforce centers, and county level services could be highly valuable allies in the dissemination and recruitment for ABLÉ.
- Recognition that some of the most vulnerable and marginalized populations who can benefit the most from ABLÉ accounts are not currently being reached. Those who can benefit most are not being targeted by ABLÉ vendors, and require customized and culturally sensitive approaches to saving. When a marginalized population, like people with disabilities and those living in poverty, have been provided a pathway to saving in a way never available before, it can take years to build trust and basic knowledge, but worth the investment.

**Question:**

Dr. Nye-Lengerman, thank you for your and your colleagues' work on the Family & Individual Needs for Disability Support (FINDS) Survey. More than half of the caregivers surveyed found it difficult to find direct support professionals to assist with care. **What can Congress do to address this workforce crisis? Is access to such care available in rural communities? What other reforms are needed to provide adequate support to caregivers, particularly in rural areas?**

**Nye-Lengerman Response:**

This direct support workforce crisis has been coming for decades. Policy makers and their allies have been slow to make finding and implementing solutions a priority. It will take courageous leadership within the Administration and Congress to fund and ensure implementation of targeted solutions to address this crisis. Without bold and swift action, Medicaid Long Term Services and Support (LTSS) system is threatened for all people who rely on it to meet their most basic needs. The President's Committee for People with Intellectual Disabilities encourages the Administration to consider the following Recommendations as possible contributions to resolving the direct support workforce crisis. We urge that the actions and programs presented here be developed and implemented, and that their outcomes be evaluated.

1. The U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services should ensure through review of Home and Community-Based Services Waivers or regulation that states include sufficient Direct Support Professional wages and compensation packages in their rate-setting methodologies for long-term services and supports to people with intellectual and developmental disabilities.
2. The U.S. Department of Health and Human Services, Administration for Community Living should provide technical assistance and financial or programmatic incentives to states to promote the use of technology solutions in long-term services and supports, such as remote monitoring, sensors, robotics, and smart homes, to create efficiencies, reduce costs and support community living for people with intellectual disabilities.
3. The U.S. Department of Health and Human Services, Administration for Community Living should provide funding to states through grants and contracts to develop, implement and evaluate comprehensive programs designed to provide training and technical assistance to employers that focus on improving business acumen to reduce Direct Support Professional vacancy rates, improve retention and promote efficient, high-quality long-term services and supports for people with intellectual and developmental disabilities.
4. The U.S. Departments of Education, Health and Human Services, and Labor should create grant programs and financial incentives for states to expand the pool of Direct Support Professionals through recognition programs, grassroots campaigns and training efforts designed to expand awareness about the profession and encourage greater participation by people with disabilities, men, retirees, and young adults across diverse racial, ethnic and cultural groups.
5. The U.S. Department of Health and Human Services should work with states to expand utilization of self-direction in long-term services and supports so that family, friends and neighbors can be hired as Direct Support Professionals.
6. The U.S. Department of Labor through the Bureau of Labor Statistics should investigate ways to recognize "Direct Support Professional" as a distinct occupation title and provide routine labor statistical reporting on this occupation.

7. The U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS) should ensure through regulation and review of Home and Community-Based Services Waivers that states identify provider qualifications that recognize Direct Support Professionals as skilled practitioners who are community navigators, facilitating greater community and economic involvement for people with intellectual and developmental disabilities. Additionally, CMS and states should Report to the President 2017: America's Direct Support Workforce Crisis 10 ensure that compensation rates are aligned with appropriate status, value, respect, a living wage and benefits.
8. The U.S. Department of Health and Human Services, Administration for Community Living and Centers for Medicare & Medicaid Services should develop federal standards and work with the Department of Labor to implement specialized credentials and professional development opportunities for Direct Support Professionals, ensuring: (a) that people with intellectual disabilities are trainers and mentors, (b) that programs are focused on competencies specifically identified for DSPs, (c) that completion of training to meet standards is voluntary and occurs post-hire, and (d) that the credentials result in increased wages and access to benefits for DSPs.
9. The U.S. Department of Labor should engage the broader American workforce system to find solutions to this crisis by using community colleges and American job centers to develop and invest in career training and credentialing for Direct Support Professionals.
10. The U.S. Department of Health and Human Services and the U.S. Department of Labor should engage the business community and provide grants and other incentives to states to develop online matching registry services and other creative options to match people with intellectual disabilities and their families who need help finding available DSPs. Unfortunately, due to the significant variation in state Medicaid programs, state's approaches Medicaid expansion under the ACA, and investment in self-directed funding options under Medicaid, access to direct support workers and home care can be very limited in certain parts of the country. Rural areas may also be disproportionately affected by the direct support workforce shortage as there may not be an infrastructure of providers or organizations that support direct care or in-home support. States are given a certain level of autonomy from CMS which allows for variation in state and local level implementation of Medicaid services, at times this can be a useful way to meet state or regional needs of a population, but without specific federal guidelines, the variation can also lead to significant disparities in access, service quality, and wait lists.

Possible reform pathways targeting rural areas could include but are not limited to (see report below):

- Worker-owned cooperatives
- Worker access to transportation
- Direct Support Worker registries
- Telehealth or tele-homecare
- Mobile day and support services (shared worker programs)
- Offsite monitoring or assistive technology monitoring
- Paid family caregiving options

Additional resources for review and consideration: CMS Strengthening Rural Workforce Report: <https://www.medicaid.gov/medicaid/ltss/downloads/workforce/rural-area-issue-brief.pdf>

Pilot study on rural workforce crisis: <https://homehealthcarenews.com/2018/08/home-health-providers-to-tackle-rural-workforce-crisis-in-new-pilot/>

National Workforce Data Center: <https://phinational.org/policy-research/workforce-data-center/>

**Question:**

For young people with disabilities, access to meaningful work experiences has been found to greatly improve their likelihood of obtaining employment as adults. Dr. Nye-Lengerman, you have also cited the importance of creating high- quality opportunities for youths with disabilities, including internships and part-time jobs. **What can we do to provide young adults with disabilities with meaningful work experiences? What constitutes a “high quality” work experience for these young people? What other factors can increase young people’s likelihood of employment as adults?**

**Nye-Lengerman Response:**

The Workforce Innovation and Opportunity Act (WIOA) of 2014 for the first time provided many of the key provisions needed to prioritize employment opportunities for youth by directing a certain percentage of Vocational Rehabilitation funds to serve youth, investing in pre- employment transition services (Pre-ets), emphasizing work experiences before leaving high school, and prioritizing of competitive integrated employment in the community (as opposed to facility based or sheltered workshop programming). States only very recently, July 2016, received federal guidance on the implementation of WIOA and need adequate time for full deployment and implementation. However, WIOA as it is currently written is at risk. On May 9, 2018, the Secretary of Education notified the public of her intent to issue a notice of proposed rulemaking to amend the regulatory definitions in the WIOA implementing regulations, 34 CFR part 361. To project the current and future investments of WIOA, and to give adequate time to states to fully implement WIOA, I would not recommend or support the reopening of proposed rulemaking. Potentially diluting the language or expected outcomes of competitive integrated employment, paid work experiences, provider accountability, etc. could undermine the effects of the legislation and set back employment opportunities and expectations for youth with disabilities in the years to come.

Numerous research studies, academic literature, and practice experience reveal similar features of high-quality work experiences for both youth and adults with disabilities. Collectively the following represent features that have been found to be critical components of positive, high- quality, employment for people with disabilities:

- Wages at or above minimum wage
- Employment in integrated or community settings with people without disabilities
- Access to benefits such as paid time off, retirement, or employer incentives
- Jobs with similar expectations for employees with and without disabilities
- Opportunities for advancement
- Longevity on the job
- Decreased dependence on public programs such as SSI, TANF, Medicaid, etc.

Literature also suggests that people with disabilities report that the following also contribute to their satisfaction, longevity, and commitment to a job which result in high-quality employment:

- Feeling part of a team
- Given responsibilities
- Access to training and or continuing education
- Access to reasonable accommodations as needed
- Treatment as an employee first, and not just an employee with a disability
- Being treated the same as other employees
- Having a sense of belonging and purpose
- Being respected by coworkers, supervisor, and or customers
- Having the ability to choose where they want to work or pursue a career



There are also a number of additional factors that have been identified in the literature as facilitators of employment post-high school. These examples have been found to have a positive effect on employment outcomes for people with disabilities and include but are not limited to:

- Paid work experiences while still in high school
- Personal and stated belief of parents and educators on if the youth is able to work
- Access to job training programs
- High expectations of support team members (parents, educators, social workers, etc.) on workforce participation
- Personal expectations and belief in self (self-advocacy)
- Individualized Education Plan (IEPs) with targeted employment goals and outcomes
- Utilization of place and train models for work experience as opposed to train then place models
- Beginning the transition process in Special Education prior to age 16
- Volunteer experience
- Use of supported and customized employment approaches
- Decreased dependence on assessments to determine work readiness, place and train models (on-the-job training) as a first approach
- On-the-job experiences, and or work trials
- Access to multiple work experiences in high school to develop preferences, interest, and skill
- High school and transition curriculum focused on independent living and employment as outcomes
- Access to long term job supports such as follow along, job coaching, etc.

Thank you for the opportunity to provide additional input to the Senate's Special Committee on Aging. Please feel free to contact me with any additional questions or comments about my submitted remarks.

Respectfully submitted by:  
Kelly Nye-Lengerman, Ph.D, MSW, LGSW  
University of Minnesota  
September 5, 2018



**Prepared Statement of Benjamin Wright, Father and Business Owner,  
Wilmington, NC**

Chairman Collins, Ranking Member Casey, distinguished members of this committee, thank you for inviting me to testify this morning. It has been exciting over the past few years to witness the passing of the ABLE Act, the ABLE to Work Act and the ABLE Financial Planning Act, spearheaded by Senators Burr and Casey. While there is still much work to be done, such as signing the TIME Act into law, I want to thank everyone on this committee for all that you have done and continue to do for people and families living with intellectual and developmental disabilities (I/DD).

As the father of four children, I spend a lot of time thinking about their futures, especially what life might look like after high school for our two youngest children, Beau and Bitty, who have Down syndrome. As most of you know, it is estimated that over 70 percent of adults with I/DD are unemployed. That is a staggeringly high unemployment rate that should not be tolerated in this country. Imagine any other group where seven of ten people didn't have jobs, people would take to the streets, and yet in regards to this group of unemployed people, there is no outrage from the majority of the American citizenry, only bewilderment on the faces of those who endure this discrimination and hopelessness in the eyes of those who love and advocate for them.

It begs the question: Why the complacency? I believe what we are really dealing with is not a classic unemployment problem driven by the economy, but a bona fide social and cultural problem. Doesn't it seem that people with I/DD are not ascribed the same value in our society as those of us without disabilities? What other group of law-abiding citizens can be paid a sub-minimum wage just because of who they are?

And yet, paradoxically, before dinner tonight, every one of us in this room could acquire the equivalent of an intellectual or developmental disability due to an unforeseen event—and then what? Having a disability is nothing to be ashamed of; it's part of the human condition, so much so that the U.S. Census reports that one-in-five Americans has a disability. Yet, here we are—with an eye-popping 70 percent unemployment rate.

So, what can we do? I believe if we can find ways to help people without I/DD see the intrinsic value in people with I/DD accepting and including them should come more naturally.

My wife Amy and I have given this a lot of thought. So much so that two years ago, we decided to open a coffee shop called, Bitty & Beau's Coffee, where we employ almost 80 adults with I/DD across three coffee shops and everyone earns above minimum wage. Initially, we thought this was a great way to reduce the unemployment rate. However, we quickly realized that the real power of the coffee shop was its ability to show people without I/DD what is possible. The point of Bitty & Beau's Coffee is not that people with I/DD can work in coffee shops, but that people with and without I/DD could and should be working together—shoulder to shoulder—in almost every type of business.

People need a fresh perspective on this issue. They need to know and understand that people with I/DD are not broken. What is broken is the lens through which we view people with I/DD. Bitty & Beau's Coffee is a new lens—and it is changing the way people see other people—offering a new perspective that once seen—cannot be unseen.

If the goal of this hearing is to support economic stability and self-sufficiency as Americans with disabilities and their families age, efforts such as ABLE and addressing policies that inhibit work for people with disabilities are important. However, we must also resolve to help people without disabilities see people with disabilities, like my children, Bitty & Beau, as worthy of that charge.

Thank you for your time.

**Questions for the Record  
To Benjamin Wright  
From Senator Jones**

**Question:**

What can we do to encourage other employers to hire individuals with disabilities and to create accessible workplaces?

**Answer:**

My proposed solution is a 3-step hiring practice. The concept is to make the solution so straightforward, unobtrusive and compelling that business owners will see this hiring practice as one they must adopt—because at a minimum, it’s good for the bottom line. Once you give business owners a business reason to hire people with disabilities, they will find over time, that hiring people with disabilities is not only good business practice that positively reshapes the culture of their workforce, but one that also begins to solve the chronic epidemic of unemployment for adults with disabilities.

If every small business in the United States hired just one adult with a disability, about 50 percent of the roughly 60 million Americans living with disabilities would find themselves hired, most of them for the first time. While my proposal may not immediately result in a living wage, it is a start. Most importantly, it provides people with disabilities entry into the labor force and a shot at more hours, development and responsibilities. While every hire may not be able to earn a living wage, a supplemental wage can have a substantive, positive impact on the lives of people living solely on SSI/SSDI, and on the lives of their families.

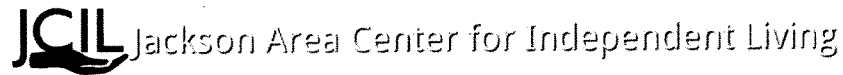
- Step 1—Offer business owners a tax credit for 1 year, equal to the payroll for one employee with a disability. The employee with a disability must be hired into competitive, integrated employment (at or above minimum wage; working with non-disabled co-workers) for at least 100 hours/year, on average. That’s only 2 hours/week.
- Step 2—After the first year, offer the business owner the terms of “Step 1” on a second, additional hire of a person with a disability. (Maximum: 3 hires over 3 years.)
- Step 3—After the first 3 years, offer the business owner a dollar-for-dollar tax credit on 50 percent of the payroll spent on their employees with disabilities for the next 10 years.

**Question:**

How can we support small business owners who are doing right by their employees with disabilities?

**Answer:**

Apply the same business incentives, as above described, retroactive 3 years.



Testimony of Edward Mitchell, MBA  
 Before the U.S. Senate Special Committee on Aging  
 Wednesday, July 18, 2018

Hearing on Supporting Economic Stability and Self-Sufficiency  
 As Americans with Disabilities and Their Families Age

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

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

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

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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

**Questions for the Record  
To Edward Mitchell, MBA  
From Senator Jones**

For young people with disabilities, access to meaningful work experiences has been found to greatly improve their likelihood of obtaining employment as adults. Mr. Mitchell, in your testimony you cited the significant impact of your first job after your disability occurred on the rest of your career. Dr. Nye-Lengerman, you have also cited the importance of creating high-quality opportunities for youths with disabilities, including internships and part-time jobs.

**Question:**

**What can we do to provide young adults with disabilities with meaningful work experiences? What constitutes a "high quality" work experience for these young people? What other factors can increase young people's likelihood of employment as adults?**

Hello, Senator Jones, thank you for taking the time to read my written testimony and hopefully these follow-up answers that I provide along with the guidance of some of my the mentors will aid you in your decision-making.

**Answer:** Senator Jones meaningful work experience as I reflect on my life experiences, comes from my mother and father parenting instilled in my brother and I growing up. As you know I stated about my first job working at Little Caesar's pizza in Jackson Tennessee for the newly opened franchised. I was able to land this job on my first interview due to several volunteering experiences. One of the many volunteering opportunities that I've experienced that I will briefly talk about would be every Memorial Day weekend for three days from 8 AM to 11 PM volunteering for SAACA African Street Festival Memorial Day weekend. The Society for African-American Cultural Awareness is a group of African-Americans with a common goal. SAACA is a non-profit organization dedicated to enhancing the level of cultural awareness in Jackson-Madison County and the surrounding areas in Tennessee.

SAACA operates under the guidelines that are set forth in its by-laws and has its four (4) main objectives to 1. Promote a positive awareness and appreciation of African-American culture; 2. Educate and entertain members of the African-American community in particular and the larger community in general; 3. Provide an economic opportunity for African-Americans; and 4. Foster an appreciation for ethnic and cultural diversity. Working every Memorial Day weekend was instrumental in helping me forge ahead while gaining practical knowledge of what it takes to run a street festival before and after my disability, it's not just all fun and games. I was expected to carry my weight and help the festival proceed without a hitch, which means that doing my fair share of work despite my disability. However, as I've come to learn through this type of experience not only looks great on resumes and college applications, it helped me develop the real-world skills necessary for the future. Although many first-time volunteers typically help with cleaning, setting up, and assisting festival-goers, the African St., Festival along with many others events allow individuals to offer their skills in helping artists and other cool opportunities like, VIP Assistants which entails work with organizers and other special guests, helping them navigate where to go, answering their questions, and solving problems. Stage Assistants are vital to helping performers before and after their set, due to time crunch getting on and off stage and set up for the next performer. One of the most useful is being a gopher, in this capacity; just do whatever is needed at a specific time or place, which can fluctuate depending on the needs of the festival organizer.

Having this kind of responsibility put into the lap of a young person helps develop them over time and eventually, these experiences will manifest themselves in great interview skills as well as dealing with the rigors of their first-time job. Rounding back to meaningful work experience is critical for young individuals with disabilities to get out in the world and experience working. It would be great if organizations and cities that host festivals and other events in their respective local communities will put forth the best effort to hire individuals with disabilities to be volunteers so they gain that practical experience. What is very advantageous with being a volunteer is they can learn from their mistakes in a nonjudgmental environment and help build upon those mistakes so once they are put into the leadership roles and apply for their first-time jobs the anxiety of messing up would not be so extreme.

While volunteering was a hugely instrumental in my life also joining the *National Association for the Advancement of Colored People* youth chapter and eventually going on to be vice president for a term and president for a term. Going to different conventions with NAACP help me develop a network of adults to help mentor me but also that I could emulate. My story is a little bit different than other young individuals with disabilities because I have not been disabled all my life, my injury occurred when I was 16 so I was able to see both sides of being able-bodied and now living with the disability. I was so eager to get my first part-time job at Little Caesar's pizza because I had an older cousin that started working at the age of 16 at Kroger's in Cincinnati Ohio. I thought it was the coolest thing ever to be able to work and not rely on an allowance from your parents. After being injured and having to spend time away doing therapy between my 10<sup>th</sup> and 11<sup>th</sup> grade year of high school, I encountered many different individuals with disabilities at different stages of their life at the Shepherd Center in Atlanta Georgia. Those that had been injured for quite a bit of time kept preaching was never to be reliant on the government and if you have the ability to work do it to the best of your ability. Nobody wants a handout and you shouldn't be expecting one was made abundantly clear by the actor *Daryl "Chill" Mitchell* who has a spinal cord injury and went right back to acting after he finished up at the Shepherd Center. *Daryl* currently has reoccurring roles in several different motion pictures as well as TV shows such as *NCIS New Orleans* and *Fear the Walking Dead*. I was blown away by his testimony but also his resilience of continuing to be an actor while at the time I had no notion of going into acting. That's the reason why hit the ground running once I arrived back home and at my part-time job with *Little Caesars*. As long as there are employers out there willing to give individuals with disabilities a shot at working part-time jobs, football games, festivals, and other meaningful work experience. Sometimes all it takes is just a few minor reasonable accommodations to make any job or volunteer experience worthwhile.

**Question: What constitutes a "high quality" work experience for these young people?**

**Answer:** High quality work experience is a multilayered issue which will be a four-prong approach. High school seniors, as well as those in their first three years of undergraduate college, need to be focused on gaining high-quality experience. I have noticed this time and time again, from not only being an undergraduate but while also working at my college post-graduation. No matter the student but even more critical for individuals with disabilities internships are key career opportunities. First reflecting on myself I was unable to participate in summer internships while in college due to the fact that I was using those three months to help better myself by doing physical therapy and occupational therapy, as well as locomotion therapy for my legs. One of the many sacrifices individuals like myself that have private insurance do, we try to use those summer months to rejuvenate our bodies as well as to stay active in many of the spinal cord rehabilitation centers so that if stem cell research became available or there is some type of new treatment for spinal for injuries we will be able to be enrolled

After completing my Masters, I felt stagnant in my career path and that's when I was let go from Lane College. It was at that time I decided to change my career path and start searching for a new career. During this time of being unemployed for the first time in life I started searching far and wide and stumbled across USAGOV

jobs and self-identified as an individual with a disability and applied for NASA's internship for people with disabilities, although I never heard back from the program but it led me to continue my search not only for government jobs but also other internships where there was a strong focus on diversity and inclusion especially for those with disabilities. In the mist of the search, I stumbled across and applied for the **NASCAR Diversity Internship Program. After going through the process and interviews inevitably made it one step away from being selected but during the final phase due to the date of my graduation with my Master of Business Administration I missed the cut off line making myself ineligible, I would have been one of the first interns with "visible disability" to participate.** Undeterred I continue to look for more opportunities even local to aid in my quest, I also traveled to Memphis several times to attend the Multicultural & International Career Expo while I made a lot of networking opportunities, one of the things I kept hearing that I was overqualified and others when pressed on reasonable accommodations they were left perplexed on the issue. While searching my LinkedIn I saw an opportunity for an internship with the Jackson General's Minor league baseball team, while I didn't get the internship because it was no longer available I was offered a new position as a fan relations coordinator. While this was only part-time I realized it could potentially lead to full-time employment with a professional sports team I can rest on potential. This propelled me to attend the Nashville Predators Breaking into Sports workshop hosted once a year. This event brings college students and professionals together collaborating in workshops and lectures with industry leaders in all facets of sports. This event concludes with a four hour career expo with those industry leaders looking for interns as well as experienced workers for those front office, operational jobs, and business affairs that make the games possible besides from working hands-on with the players.

After attending my first Breaking into Sports workshop, a college friend and fraternity brother just completed his Master's degree out-of-state and he had run into a young professional that said he needed to join the National Black MBA Association and go to one of their career conferences takes place annually.

Sen. Jones if you are unfamiliar with The National Black MBA Association let me tell you a little bit about NMBAA and how it strives to present high-quality careers and work experience not only for MBA graduates but also college graduates. This professional development and executive leadership conference engage more than 9,000 business professionals and nearly 450 corporations annually for networking, on-site corporate recruitment, leadership development, and career opportunities. The conference boasts an on-site exhibit hall with 300 companies with products or services targeting business professionals. The NMBAA conference is the largest, most diverse professional conference in the U.S. for MBA graduates; and attracts corporate executives, individuals with graduate degrees, and undergraduate students, who come together for five full days of intense learning and engaging programming. Topics and content at the NMBAA career Expo provide opportunities for intense on-site job recruitment, talent development, salary negotiation, professional growth, career advancement, entrepreneurship, and job interview preparation.

After making arrangements and enlisting the help my parents to make sure that I could attend the conference in 2015 in Orlando, and I was overwhelmed with the high-quality career opportunities and workshops that were available to those that signed up and paid for the conference. Going to the different workshops and lectures on how to better myself and really boost my career was outstanding and what really surprised that a lot of individuals as well as myself as I was the only one with the visible disability, especially a chair user to attend the conference. The last two days were devoted solely to the career Expo and I was shocked and amazed to be among the 300+ companies hoping to diversify their workplace. Career companies such as IBM Corp., Lockheed Martin Corp., PepsiCo Inc., Twitter Inc., Bank of America Corp., FedEx Corp., Starbucks Coffee Co., Marriott International Inc, and BMO Financial Group. And these aren't just entry-level jobs, either. Many of the companies attending the event are looking to fill internships, entry-level, leadership, and director roles. It was an overwhelming experience I navigated the waters and was able to make a lot of networking opportunities and talk to hiring recruiters. The best

thing that I gained from my first conference was to be better prepared my second conference and now that I know what to expect from the career Expo the next year in New Orleans. I vowed to myself that I would apply what I learned in the workshops so that I would be even better prepared with several different types of resumes in a more polished elevator pitch and brag book.

The career Expo put on by NMBBAA exemplifies what it means to have high-quality work experience but also with these career minded companies in the forefront that want to talk to each person that drops by their booth but also the personal touch with the on-site recruiters. In this virtual age of being only a number and not knowing where your resume goals after clicking send it was refreshing being able to meet HR managers as well as the recruiters to have on the spot interviews for jobs but also internships. The wealth of knowledge in that Expo Hall is a sightsee and there is no reason why anyone should leave they're without some type of lead on a potential new job.

The current president of the National Black MBA Association Jesse Tyson is a mentor of mine and former executive at Exxon Mobil among other companies in his illustrious career. He would be thrilled to hear from you and tell you more about the National Black MBA Association that only the president of the Association can do. I look at this as an avenue for individuals with disabilities are in the process of achieving their undergraduate degrees and Masters to join associations such as this. Associations such as this where opportunities for face-to-face contact and meet other like-minded individuals that will possibly mentor the individual and look past their disability. I learned that firsthand meeting with recruiters was thrilled with being asked to talk to me and learn what I can bring the company and not that I was individual with a disability looking for a handout; I was there seeking career employment.

Not every conversation with the recruiters went according to plan because some jobs were just beyond the nature of what I physically can do such as extensive traveling, but that was only due to my disability were someone else that might not be an issue. Also, another drawback for me will be relocating to a state with extreme ice and snow due to me using a power wheelchair and a wheelchair modified van which sits extremely low to the ground.

I would strongly encourage you to attend one of the National Black MBA conferences or even lobby to have one of them hosted in your state because it is a huge revenue boost to the local economy due to this weeklong conference. It also would be extremely beneficial if you spoke with the state of Alabama's vocational rehabilitation office and strongly suggests that they push that individuals that are getting their undergraduate or Masters degree and join professional organizations such as the NMBBAA, the reach of the NMBBAA and their career Expo would ensure those individuals having their schooling paid for by vocational rehabilitation can attain higher quality internships from around the world as well as gain industry peers and mentors to help them into the future. I wish I would've been aware of this Association long before I got my master's and especially as an undergraduate. Having proactive inroads into standout internships with multiple companies so once I graduated I would've had it inside track to multiple recruiters in many different industry-leading companies. Job fairs are okay that colleges put on but career fairs such as this are life changing, in the scope of how you view yourself along with the other thousands of individuals that attend the Career Expo at the National Black MBA Association every year. I encourage you to attend one year and be blown away to see a career-oriented Association and expo.

**Question: What other factors can increase young people's likelihood of employment as adults?**

**Answer:** Other factors that can increase young people's likelihood of employment as adults would be a summer internship initiative. Not only is this important to youth without disabilities but tremendously important to Individuals with disabilities to job shadow with local city and state agencies every summer, sitting around every

summer while in high school and not actively involved in a part-time job or volunteer experience is extremely wasteful when those days can be put to productive job shadowing and local internships. I believe getting the students involved early is essential for their growth but also to show them what type of careers are out there. It would give them the practical hands-on experience of what it takes to be a district attorney, law enforcement official, firefighter, or many others city and state jobs that they have no idea exist or what things they might need to consider depending on their disability.

Another big factor that could help increase the employment of young people with disabilities moving forward in life is something that I was quite interested during my high school and college years but was unsure if there would be reasonable accommodations were the Senator Page programs as well as the White House internships.

One of the drawbacks that I encountered was trying to figure out if the programs were disability friendly. I was more concerned about having the time to figure out how to make it accessible or if there were any type of reasonable accommodations that could be made. I can only speak from my own experience but the times that I reviewed the different White House interns as well as different page programs from different senators I never was able to identify with someone that physical disability or a chair user. I think a change that should be implemented such as setting aside maybe one or two of those page slots or White House internships for individuals with disabilities. I can attest that individuals with disabilities might need just a little bit of time to make sure they have the right infrastructure that will allow them to take on a great responsibility like this but also to ensure that there are reasonable accommodations, so they could complete the internship/job at hand and gain that critical experience. Not only will it boost morale and show other young people with disabilities from around the United States that they too can work under a Senator or go on to Washington D.C. to be a White House intern. This demonstrates to able body Americans those individuals with disabilities are not just sitting at home wanting to collect SSI or any type government assistance. Yes, some of us may have physical limitations or other limitations but we have become the masters of our own fate and the captains of our own souls and will do whatever it takes to complete a job even if that means putting in twice the effort to get the same results as an able-bodied individual. Speaking for myself but put into the right circumstance I will not fail those that help me reach that plateau and I will do everything in my fiber to show that individual or boss that they made the right choice in me for that position and will demonstrate the unique set of talents and expertise I have to offer.

The last but one of the most important likelihoods of employment for individuals with disabilities will be connection primarily between vocational rehabilitation in Alabama for example and all of the new industries currently putting roots down in the great state of Alabama as well as long-tenured companies. Sen. Jones if you're unfamiliar with Vocational rehabilitation (VR) is a state program which assists people with disabilities to obtain a set of services offered to individuals with mental or physical disabilities. These services are designed to enable participants to attain the skills, resources, attitudes, and expectations needed to compete in the interview process, get a job, and keep a job. Services offered may also help an individual retrain for employment after an injury or mental disorder has disrupted previous employment.

The rationale behind my thinking is my own experiences and those that I have encountered from other young adults with disabilities trying to find their way in life. A direct pipeline between VR and career companies in the state needs to be established so that these young people have access to quality internships that inevitably lead to career placement for those individuals with disabilities. Individuals like myself that go on to obtain their associates, bachelors and Masters degrees with the help of vocational rehabilitation will benefit tremendously if this partnership is established. Also it will be beneficial all four entities, vocational rehabilitation, the state, the companies, and the individual.



This type of partnership will elevate the state of Alabama and vocational rehabilitation by keeping local graduates that have used those services in the state of Alabama but those individuals with disabilities will feel empowered because they know the type of reasonable accommodations they need, also by staying local in their state they won't have to reinvent the wheel for the personal supports that might be needed in order for them to accept those internships and potential job placements. Individuals with disabilities are very much rooted in the communities that they live, relocation sometimes is a daunting task. But without career-oriented jobs, communities suffer from brain drain, where individuals uproot themselves for better opportunities such as quality of life, higher salaries, and employment opportunities.

Newly rooted companies Airbus in Mobile, Aerojet Rocket dyne breaking ground in Huntsville, along with more established companies such as corporate headquarters of Encompass Health, Alabama power, Hyundai car manufacturing, BBVA Compass, last but not least University of Alabama just to name a few. These companies, as well as future companies, should want to partner with vocational rehabilitation because these individuals with disabilities will have the requisite skills from their education as well as possible intern experience from the same companies. This will make them idea company employees, but also it helps these companies not to search so far and wide for those individuals for internship programs and jobs. It really should be an emphasis on grabbing local talent but even more for those with disabilities. It helps foster the social responsibility of these companies putting individuals with disabilities to work with reasonable accommodations that are afforded to them by the Americans with disability act, but also shows that these companies are forward thinking despite an individual's disability. Those individuals with a disability are going to work as productive employees because they have earned it. This pipeline will innovate change not only for Alabama but vocational rehabilitation throughout the United States to show that despite personal limitations individuals with disabilities that go through the local pipeline of higher education, internships, with the end goal being career placement the person with the disability will obtain that self-earned satisfaction independence as well as a career that affords them the American dream of self-sufficient despite their disability.

**Senator Jones**

Mr. Mitchell, I was heartened to read in your testimony about your experiences attending Lane College. The support you received from the school is an excellent model for other academic institutions and exemplifies the value that HBCUs provide to their communities and students. Recognizing this value, I have continued to advocate for increased funding for HBCUs.

**Question:**

**Based on your experience, how can colleges and educators best support their students with disabilities? How can policymakers support schools like Lane College, and encourage others schools to follow its example?**

**Answer:** The best way I believe colleges and educators can support students with disabilities, first and foremost will be for the college president and possibly the director of student affairs to visit places such as the Shepard Center in Atlanta Georgia, the Frazier center in Louisville Kentucky and other prominent rehabilitation centers. When I first was enrolling at Lane College the institution never had an individual with a disability / wheelchair users attend or live on the college campus in its history. Dr. Wesley Cornelius McClure made it his priority to contact my former therapists at the Shepherd Center in Atlanta Georgia for them to give the common facilities inspection and order to make the campus barrier-free as possible so that I can function on campus as any other student. Dr. McClure along with the C.M.E church took that initiative which in turn allowed me to start college as a freshman to a move directly into the dormitories with zero having or distractions. I will be forever

indebted to Lane College as well as the C.M.E church for making sure that I can attend a historically black college like any other student and capturing the whole college experience.

For the college professors, it will be very beneficial having a meet and greet with the student before classes begin in the semester. This is not solely on the professor to make sure the student has reasonable accommodations, this is incumbent on the student to articulate what type of accommodations that they might have had while in high school. For some this might come from IEP's but particularly if they were receiving reasonable accommodations while in high school those are in some type of student personnel file that can easily be presented to the college professors. While things have changed since I've been in school in 2005, with it being currently 2018 the digital age has made things so much more accessible to students with disabilities, such as notation, digital PowerPoint from the professor, lecture notes, dictation software for typing long papers, and plenty more technological advances. These young adults entering college beginning their lives must account for the setting of those reasonable accommodations, and not waiting until the last minute to make adjustments. As things have changed in higher education most colleges and universities have a office that deals with disability affairs and it would be quite easy for the student and their respective department heads to come together and have a baseline of what types of accommodation were done in high school and how it can be applied to the college curriculum.

**Question:**

**How can policymakers support schools like Lane College, and encourage others schools to follow its example?**

**Answer:** An effective short-term plan in order to affect change at Lane College and other HBCUs will be gradual but in order to get there policymakers must understand the essence of why the schools are still relevant. HBCUs are more important today than ever before. These institutions were created to allow recently emancipated slaves an opportunity to pursue higher education. While times have changed, HBCUs remain relevant. These historical schools provide value in the 'HBCU experience.' a culture of caring, a culture that prepares students to contribute to their communities, a culture that builds confidence and that gives them the essence of what it means to be a minority but not let it be a crutch but a springboard into diversity. HBCUs are just not for African-Americans what they are for all students of any ethnicity. In my own personal experience at Lane College and walking among other HBCUs I've encountered a wide abundance of different ethnicities that attend because they want that tight knit feel of attending a smaller college where you are not a number but a name. That is truly important about HBCUs are a family atmosphere where you get to know your professors, and because the student population isn't so large they really get to know their students if they so choose on a one-on-one basis.

HBCUs find it quite hard to compete against major state universities due to the funds that are afforded public institutions and there must be some type of bridge to help support the schools. We can't let their numbers dwindle any lower than what they are currently are. If we continue to let the schools perish the United States and the communities at large will lose an attachment to history and the great minds that have come from the schools. It would be great if policymakers would take time to walk amongst the student body during homecoming and other school functions so they would understand and experience what it is to be on an HBCUs campus. Also while mixing and mingling on HBCUs campuses the president's, vice presidents, and Board of Trustees can really articulate what could be achieved if they had a fraction of the funds available to them as that is provided to public schools.

Last but not least it would be very beneficial if local corporations would take interest in HBCUs, there is a wealth of knowledge and opportunity that can be gained by partnering with these institutions. These partnerships

could open a floodgate of students that would be able to intern and eventually land jobs with these Companies. There might be a stigma against HBCUs due to negative portrayals in the media or general stereotypes that have been passed around for years. But until our Senators and other people influence explore HBCUs themselves, they truly don't know what it is to be on campus and to be a graduate. Some of the best minds in any career path have many great HBCUs graduates, HBCUs are welcoming to everyone, they embrace all ethnicities with open arms only wanting to do what's right and educate the students. I also reached to the institutional advancement department at Lane College and spoke with Attorney Donnell, He included a letter from Lane Colleges perspective on how policymakers can help HBCUs.

Policymakers could also support schools like Lane College and other HBCUs by adopting a modified version of Bernie Sanders plan as I will quote below.

*"HBCUs disproportionately serve students facing the intersecting effects of wealth inequality, systematic K-12 disparities, and discrimination. For those reasons, Bernie's plan permits low-income students to use federal, state and college financial aid to cover room and board, books and living expenses at all HBCUs.*

*Bernie's plan will cut student loan interest rates almost in half for everyone who is enrolled in an HBCU while increasing federal work-study programs at HBCUs to build valuable career experience that will help African American as well as other minorities students after they graduate. Those former students that have attended an HBCU at any point in time an opportunity to refinance student loans at today's low-interest rates.*

*Too many HBCUs have struggled financially in recent years from a lack of federal resources. That's why a dedicated billion-dollar fund source is needed to support private non-profit HBCUs, minority-serving institutions, and other non-profit schools to keep costs down and to provide a quality education.*

*What is also optimal about Bernie Sanders plan is that it benefits the entire school and focuses on improving the school as a whole. The plan would not burden HBCUs with red tape or too much bureaucracy making it easier for these funds to get to schools and their students. Schools would be also able to use the money for multiple purposes, especially to reduce tuition and the cost of attending an HBCU. To ensure that HBCUs are accountable for the funds received, provide rewards and continued funding for the best performing schools while providing program assistance to schools still trying to improve.*

*In addition, Bernie's plan designates federal research funds for HBCUs that will increase the number of student-led and faculty-driven research conducted at HBCUs that advances basic scientific ideas in the STEM fields of science, technology, energy, and mathematics, as well as healthcare."*

*Sanders, Bernie "Supporting Historically Black Colleges and Universities"*

<https://berniesanders.com/issues/supporting-historically-black-colleges-and-universities-and-minority-serving-institutions/>

In closing, Sen. Jones hopefully I've answered your questions fully, and I am at the disposal of the Aging commission and any other Senators for further follow-up. I'm here to serve the people of the United States in any capacity possible. It is my hope that you will continue to be a champion for historically black colleges and universities throughout the United States we can't lose that tradition of history, also thank you for all your hard work that keeps individuals with disabilities in mind. We don't want to be known as having a disability we want to be known for the abilities we possess and our talents to blaze a trail for our future.

**Prepared Statement of Jack Stollsteimer, Deputy State Treasurer for Consumer Programs, Pennsylvania Office of the State Treasurer, Harrisburg, Pennsylvania**

Good morning Chairman Collins, Ranking Member Casey, and other distinguished members of the Committee. I am Jack Stollsteimer, Deputy State Treasurer for Consumer Programs. On behalf of Pennsylvania Treasurer Joseph Torsella, I am grateful for the opportunity to appear before you today to discuss our department's ABLE (Achieving a Better Life Experience) program and how it is improving the lives of people with disabilities of all ages by helping them achieve economic self-sufficiency.

The PA ABLE program was launched by Treasurer Torsella in April 2017 after a bipartisan group of state legislators, supported by a broad coalition of advocates for the disability community, enacted strong enabling legislation in 2016. The Pennsylvania ABLE Act includes provisions exempting ABLE accounts from Medicaid paybacks and offering account owners protection from creditors in state legal proceedings. Since the implementation of the PA ABLE Act our Legislature has continued its strong support of the program by creating a state tax deduction for contributions to ABLE accounts and through an annual appropriation for Treasury to market and administer the program.

In the fifteen months since our program launch, we have seen a surge of interest for the benefits offered by the ABLE program from people with disabilities of all ages. We have a number of account owners who are working adults with disabilities who find the freedom for the first time to hold significant funds in their own account without jeopardizing their access to federal disability benefits truly liberating. We have parents of young children with disabilities saving long term for their child's future by making small but regular contributions without paying the up front fees required to open a special needs trust. We have older adults using ABLE funds to purchase adaptive technology to enable them to live more productive, fuller lives. We even have parents of account owners using ABLE accounts as estate planning vehicles to ensure their children's future financial security. Currently our ABLE program has more than 1,400 account holders with \$8.3 million dollars under management, and each of those account owners has their own story as to why ABLE is the best option for them to save, pay bills, and make debit card purchases through their PA ABLE account. We have made so much progress—but we have so much more work to do. There are over 60,000 children with disabilities in Pennsylvania; with ongoing support from federal and state policymakers, our goal is to reach as many of them as we can.

Over time, the ABLE program can provide a means for people with disabilities to achieve greater self-sufficiency as they age as long as our federal partners continue to support the program's promise. The ABLE program works for people by allowing anyone with a qualifying disability a secure, tax-advantaged way to save or invest without affecting their government benefits. It also works because the Internal Revenue Service has broadly interpreted the definition of a "Qualified Disability Expenses", thereby allowing people with disabilities the flexibility to use the program throughout their lives, since the nature of an individual's expenses change to reflect their different stages in life. Simply put, the qualified expense needs of a 25-year-old worker in many respects are very different from the expenses of a 65-year old retiree.

Right now, ABLE provides the flexibility to accommodate the changing needs of people as they age but we must ensure that remains true in the years to come. To that end, the Pennsylvania Treasury would strongly encourage the Senate to consider S.B. 817, the ABLE Adjustment Act. This bill would greatly increase the utilization of the program by allowing individuals with disabilities that started before age 46 to open ABLE accounts. Increasing the number of people with disabilities who can open accounts will strengthen the ABLE program from a fiscal perspective while allowing older adults who become disabled through accidents, chronic illness, or military service to use this tool for their economic stability and self-sufficiency.

**Questions for the Record Submitted to Jack Stollsteimer****From Senator Jones****Question:**

Mr. Stollsteimer, you state in your testimony that Pennsylvania currently has 1,400 ABLÉ accountholders, and that your goal is to reach the more than 60,000 children with disabilities in your state who could benefit from the program. Based on your respective expertise, what recommendations do you have for growing the ABLÉ program nationwide and increasing the accessibility of these accounts?

**Answer:**

Critical to growing the ABLÉ program nationwide is the passage of the ABLÉ Adjustment Act, Senate Bill 817. Passage of S.B. 817 would greatly increase the utilization of the program by allowing individuals with disabilities that started before age 46 to open ABLÉ accounts. Increasing the number of people with disabilities eligible to open accounts will strengthen the ABLÉ program from a fiscal perspective while allowing older adults who become disabled through accidents, chronic illness, or military service to use this tool for their economic stability and self-sufficiency.



---

---

**Additional Statements for the Record**

---

---

**Constituent Support Letters to Senator Collins and Senator Casey  
Hearing Before the  
Special Committee on Aging  
United States Senate  
July 18, 2018**

**Supporting Economic Stability and Self-Sufficiency as  
Americans with Disabilities and their Families Age**

---

**Written Testimony of Elizabeth A. Bechtel, Boalsburg, PA**

My name is Elizabeth A. Bechtel. I am a retired communications professional, having held positions as a magazine editor (*Town & Gown* magazine, *The Penn Stater*), internal communications (AAMCO, Educational Testing Service), and marketing communications (Penn State).

My sister Carolyn J. Bechtel, who is fourteen years younger than I am, was declared disabled before her eighteenth birthday. In 1987, after my mother died of cancer, Carolyn came to live with me. I have been very grateful for the SSI support she has received over the years and for the support available through Pennsylvania's MH/MR program. However, I was always concerned that Carolyn could not hold resources of \$2,000 or more. I have encouraged her to have as much independence as possible, to hold down a part-time job, and even to save for vacations offered through "The Guided Tour, Inc." of Elkins Park, PA. But, I worried about her future, for if she wanted to accumulate any funds that could be used for her retirement or to supplement SSI when I am no longer able to help support her, those funds would — before PA ABLE — have made her ineligible for necessary services.

For many years, Carolyn held a part-time job as a janitor at the Nittany Lion Inn on the Penn State University Park campus. Recently, her hours were cut and she found another job at a local Weis Market. (Both institutions are to be applauded for their willingness to offer employment to people with disabilities.) When she left Penn State, we learned that she had accrued a small amount of money in the SERS (State Employee Retirement System) program, which, while not enough to vest her in the program, was more than the \$2,000 she could possess.

Happily, just days before learning about the money she would receive from SERS, I saw a television promotion for PA ABLE. I had thought of consulting a lawyer to determine whether I could place some of the money my sister was earning in a trust, but after reading the ABLE materials, I chose to open an ABLE account for her.

This remarkable program can be tailored to the needs of the individual. Because my sister is fifty-nine, I am most interested in potential retirement resources, so I chose a fund that has moderate risk and some potential for growth. Had she been younger, a higher- growth/higher-risk option would have been available.



The ABLE program is proving its worth every day, allowing people with disabilities to build for a future that offers stability of services, a safety net for protection against catastrophic expenses, and the possibility of saving for a dream they might otherwise never be able to afford. A few enhancements might make ABLE programs even better:

- Allow/enable automatic withdrawal from paychecks;
- give employers the option of contributing to ABLE accounts as part of 401K plans;
- communicate information widely through all media;
- consider enclosing information in the annual Representative Payee form; and
- encourage bank officers to understand and recommend ABLE accounts.

As a sidebar—the amount of money Social Security allows an individual to have (\$2,000) has not changed in many years and should certainly be increased to compensate for inflation.

Thank you for offering this path to greater independence for people with disabilities.

---

**Written Testimony of Nancy Briski, Allison Park, PA**

My name is Nancy Briski. I am a 66-year-old mother of a 30-year-old daughter who was diagnosed as being on the autism spectrum when she was 20 years old. While she receives social security benefits, they do not cover all her expenses, so I continue to work to support her; she is unable to work.

I waited in great anticipation for ABLE accounts to be approved in Pennsylvania and immediately signed my daughter up for an account. The account is in her name and I am the responsible party. This account enables me to save any extra money I can spare for my daughter's future needs. Her future, without me, is my greatest concern, as it is with any parent of a disabled child. Prior to ABLE, any amount of money over \$2,000 each month would have affected my daughter's governmental benefits in a very negative way. She needs those benefits to survive.

I would encourage you to open ABLE eligibility to anyone with the proper diagnosis. As I said, my daughter did not receive hers until she was 20. She has met any number of older adults that are on the spectrum that are unable to support themselves and often live with elderly parents. It does not matter at what age a person receives a diagnosis of a disability that affects their quality of life. Parents should be able to save money for the future care of their children without negatively. Please do not take ABLE away.

I encourage you to hear my voice. Please continue the ABLE program and expand its eligibility requirements so that our most vulnerable citizens are not penalized. Thank you for giving me this opportunity to speak.

---

**Written Testimony of Helena Chojenski**

My name is Helena Chojenski. The ABLE program gives me a sense of independence because I can keep track of my own finances. I do not need a trustee, nor do I have to pay the higher maintenance costs associated with a special needs trust.

I do not have to spend down my already limited money on lower priority expenses just to maintain the SSI resource limit. I can save funds for very important essentials such as uncovered healthcare expenses or housing expenses that I will certainly incur down the road. The fact that both my relatives and I can contribute to the ABLE account is very significant.

Without this program, I would have risked losing my SSI benefits. SSI guidelines can be complicated to understand for a person who has trouble affording an attorney or financial advisor. The ABLE program gives me a good way to manage my funds.

---

**Written Testimony of Stephen Foery**

My name is Stephen Foery. Attention deficit hyperactive disorder (predominantly inattentive subtype) plus bipolar disorder (rapid cycling, with non-violent relation to the mood) compose my disability. I graduated college from the University of Southern California with a degree in Cinema-Television, Critical Studies in the spring of 1998. While the nascent traces of my disability existed in my youth, its disabling onset did not begin until the summer of 2001 when I was 25 years old. That was when I first experienced a complete mental breakdown resulting in hospitalization and that ultimately got me to move back in with my mom and stepdad across the country in West Chester, Pennsylvania. Prior to that time, I lived a reasonably normal life and enjoyed some success as a filmmaker living in Los Angeles.

My disability was not easily diagnosed. From 2002 through 2006, I was hospitalized more than a dozen times for three suicide attempts and chronic, treatment-resistant depression. I had electroconvulsive therapy. My disability periodically stabilized on different medicines that worked well enough for me to be employed full-time, for a time, three times: two jobs at publishing companies and one job in retail. However, in 2006, following release from the hospital for my third suicide attempt, the discharge worker suggested that I apply for Social Security Disability. I did as they suggested, and received SSDI income from May 2006 onward. Also at that time, I began receiving Medicare and Medicaid healthcare and was placed in the care of a community mental health organization where I started being treated by my psychiatrist.

I went back to school, half-time, in 2007 for the post-baccalaureate Premedical Program at West Chester University. While attending school I worked flexibly, part-time as a bookkeeper for an interior decorator and for the owner of an art gallery/framing shop. I was not making enough money to consider saving, and survived on SSDI, SNAP benefits, help from my mom and the luck of finding an extraordinarily affordable, one-bedroom apartment close to school

and work. I switched my major to chemistry around 2010 and served a summer internship with National Foam in R&D making and testing fire-fighting foam. I did not complete the chemistry major because in early 2012, my disability struck again and I suffered a wild bout of mania. That is when my psychiatrist started administering a once-monthly "depot" injection of mood-stabilizing medicine that virtually knocked me out at first.

I worked minimally in 2012 as my psychiatrist titrated me to a tolerable dose of the depot injection. In 2013, with a good medicine regimen, I answered a want ad for a Church Administrator position at the Unitarian Congregation of West Chester and they hired me. I felt truly employed for the first time in my life. I worked regular hours for 19 hours each week and made \$12 an hour or \$912 per month, before taxes. My income did not disqualify me for SSDI or Medicaid, though I paid \$60 per month for PA Medical Assistance for Workers with Disabilities. My SNAP benefit decreased to approximately \$3 per month. When working as a Church Administrator, I felt some security with my employment and "did the math" to see how I might be able to grow in the position and earn more money, and to see how I might get myself off of disability and pay into it instead. I found this would have required a quantum leap from making \$11,000 a year to making \$33,000 per year in order to afford insurance and an anticipated prescription co-pay of \$300 per month. The depot injection is not cheap and retails for approximately \$700 per monthly dose.

In late 2015, I learned of the ABLE Act and wondered how I might be able to take advantage of an ABLE account. I figured that, at least, an ABLE account would allow me to save up for an emergency fund without fear of going over the state asset limit for Medicaid. In addition, at this time, my psychiatrist retired from the community mental health organization where I was seeing him, citing what he said were emerging conditions making it impossible for him to deliver even the minimum standards of care. I followed him into private practice, paying, personally, an affordable fee of \$85 per month to see him. I held the job as Church Administrator, performing excellently through two ministers until it was found that I was incompatible with the third, a settled minister the congregation found to replace the one that hired me. Accordingly, I was fired in March 2017. I was paid through the end of March; but, outside of that, I had no savings.

ABLE accounts became available in Pennsylvania in April of 2017. I opened one in May with \$50 I had earned doing a freelance graphic design job. Otherwise, with the sudden loss of \$912 per month, I was living off credit cards to make ends meet. However, this was not a terrible time for me, because I felt inspired, almost driven to formulate a fabric softener for people with allergies and chemical sensitivities. Also, I met a young friend, 28 year-old Adil, a new immigrant from Morocco with an Associate's Degree in chemistry; and, also, I met the man who is now my husband, Johnny, who came here from China to get an MBA at the University of Delaware. Both of them came to the United States because same-sex couples can get married here. They helped me with the fabric softener and I obtained a U.S. Trademark for the name, Cloudia Plus® that we share. In the middle of this new activity, my stepmom gifted me some money that I used to pay for part of Johnny's USCIS fees and the balance I placed in the ABLE account. In fact, my contributions totaled \$838.41 at the end 2017 with a fair market value of \$849.34.

Johnny and I got married November 2, 2017. He had to return to China one month later to attend to the mourning of the death of his grandfather. We expected he might be able to return earlier; but his USCIS parole took some time and he is returning in five days. I obtained a new job working from home as a Google rater for Lionbridge Technologies of Walham, Massachusetts. I make approximately \$392 per month, before taxes. I celebrated Christmas and New Year's holidays with my good friend, Adil, in so much as he could celebrate, late at night, in between the two jobs he consistently works. I filed for bankruptcy for \$21,213.14 that was discharged June 14, 2018. My new job has a default, matching 401 (k) that I am learning about. My psychiatrist is retiring from practice, completely, in August. The ABLE Account savings have paid for my visits with him and medicine co-pays up to August, almost exactly. I re-visited the community mental health organization where I started seeing him back in 2007 and their medical team refused to treat me with my current medicine regiment. I am starting with a new psychiatric evaluation at a new community mental health organization twice as far away on July 26, 2018.

ABLE Account actually helped me to save to pay for visits to my psychiatrist and thus the continuation of a medicine regimen that has proven workable and with good success, to this point. Also, ABLE Account, when first an inkling, got me thinking seriously about my finances and saving for an emergency fund in an account that is slightly less accessible than say, a bank account with same day withdrawals—that is a psychological advantage! In addition, thinking of ABLE Account as a conceptual investment vehicle for support for people whose disabilities prove more extensive to treat than mine do, I have hoped my participation with it strengthens it for others.

---

**Written Testimony of Annette Holland, Luzerne County**

I am a Luzerne county resident who was qualified to receive SSA–SSI benefits as of June 2016. I received a letter from Social Security about two months after my first payment, which stated the requirements for savings accounts; I had to keep my savings balance below \$2,000. This rule does not give recipients the ability to save enough money for medical expenses, purchasing a home, or money for a new family member or new vehicle. With PA ABLE, it offers me a way to save for these things and still meet SSA requirements. I have always wanted to return to school part time and can do that because of my PA ABLE account.

---

**Written Testimony of Keith and Maria Kerns, Harrisburg-Steelton, PA**

My wife Maria and I are retired and have legal custody of Skylar J. Taylor who will be 13 on August 17 this year. Skylar is profoundly autistic, has cerebral palsy, epilepsy, OCD, ADHD and is non-verbal. He had a stroke in utero when his mother, eight months pregnant, was in a car accident in Texas. He had a trust set up in Texas because of a settlement of a lawsuit. His father, our son, passed away in July 2010. We brought his mother and Skylar up from Texas about a year later when we were told he would be put into foster care in Texas. Eventually his mother was put into rehab twice, arrested, and imprisoned for felony child endangerment. We took Skylar from her and hired an attorney getting legal custody in May 2014.

The ABLÉ account is in Skylar's name and I administer it, as well as his survivor benefit. Maria is a retired teacher and I am retired from the State of Pennsylvania. We had a challenge in learning how to deal with an autistic child, who had no early intervention, and how to get him benefits. We eventually got him Medicaid, and as you might imagine, many doctors and therapies. After much hard research and work, the Central Dauphin School District agreed with us to enroll him in the Vista School in Hershey, PA, a school for autistic children. It is a fabulous facility and he has grown so much since he has been there.

I opened an account for his survivor benefit in the Pennsylvania State Employees Credit Union, PSECU. We were very careful with his money while trying to consider the long-term care he would need. We decided that at our age, we should get him all the benefits we can since we have 10 other grandchildren and we travel a lot to see them. We got an appointment with Social Security in Harrisburg to apply for disability benefits, which would give him an additional \$90 per month. The meeting lasted only a few minutes. When they asked how much money he has in the bank, I responded proudly that I had \$2,800 in his account, hoping they would be happy with our good stewardship of his money. They said he does not qualify and might even lose his Medicaid benefit since \$2,000 in equity was the cut off for being able to qualify. We were shocked. We are retired and although we have decent health benefits, we could not afford all the medical care he needs. The copays alone would be thousands of dollars per year.

*We had to spend his money to get and keep his benefits!* Skylar has two iPads. He uses one for leisure and other has a program he uses to communicate. He took one into the bathtub to wash it, so it was easy to get him under the \$2,000 limit at that point. However, having to spend Skylar's money just to keep his benefits made no sense to me.

We got another appointment with Social Security and discovered that the settlement for the accident in utero that was in a trust in Texas disqualified him. In the meantime, Vista School employees told us about the ABLÉ program. We looked into it, but Pennsylvania had not set one up yet.

We hired another attorney to get the Texas Trust moved to Pennsylvania. It was a substantial amount of money and we had no idea where to put it and feared it would kill his Medicaid benefit again. We were considering opening an ABLÉ account in Ohio when Pennsylvania finally passed

the needed legislation. I opened an ABLE account as soon as possible. It took a while, hiring an additional attorney in Texas, but we were able to transfer the Texas trust into the ABLE trust. We had to do it in two phases since ABLE only allowed a deposit of \$14,000 annually at that time.

The ABLE program has been a godsend. It allows us to save Skylar's money without fear of losing his benefits. When I get close to \$2,000 in his PSECU account, I can simply transfer money into his ABLE account. We also ask friends and relatives to give him cash or checks for presents, which we then put into the ABLE account. ABLE also allows us access when we need a special item for him. For example, we recently purchased a \$2,000 special needs stroller with ABLE funds. Therefore, when we take him to places like Hershey Park, he does not have to walk all day because he has braces on both feet. He also tends to wander due to his autism and it allows us to keep better control when we are in crowds.

The only recommendation I can make is to increase the amount that can be deposited in any year. It would have been nice to be able to transfer the entire amount of his Texas trust at one time and because having money in the Texas trust for an additional year could have jeopardized his services.

Thank you for this opportunity. We have been raving about the ABLE program and I have recommended it to a few friends who are in the same situation that we are.

---

**Written Testimony of Mary Ann T. Kline, Hazle Township, PA**

My name is Mary Ann T. Kline and I am the mother of PA ABLE account holder Andrew C. Kiss. My son, Andrew, is 26 years old and was diagnosed with an autism spectrum disorder classified as Asperger's when he was about 10 years old. Along with this diagnosis, he has a combination of developmental and intellectual disabilities, which, at times make life challenging for him, especially in the area of money. Currently, Andrew lives on his own in a small studio apartment, in the Hazleton area, about three miles from me. He has a small part-time job at Gould's Supermarket in Conyngham, PA, which employs people with disabilities. He also receives Social Security benefits due to his disability and, services through an autism waiver with Luzerne County Mental Health/Developmental Services, which assist him to live independently. He lives on a fixed income, which I monitor on a regular basis.

Saving money is a difficult task for Andrew when it comes to the future. Being a recipient of Social Security, and prior to becoming a member of PA ABLE, Andrew could not have more than \$2,000 in his combined checking and/or saving accounts. This made it difficult for him to put money aside for specific goals such as transportation needs, unforeseen health bills, and maybe one day owning a home. No one knows what the future can hold and people receiving any type of Social Security income were at a deficit for planning for the future due to the monetary limits imposed on them, prior to the inception of PA ABLE. How can one put money aside for the future to make life a little more comfortable with this limitation special to Social Security recipients?

I heard of PA ABLE a few years ago from an article I read on-line about a savings program in Virginia, which enabled people collecting Social Security to save money and not incur penalties on their benefits. This program was not up and running in Pennsylvania when I read about it, but was in the works. Being Andrew's Mom and knowing his monetary challenges, I knew if there was a way Andrew could save for unexpected expenditures, I sure wanted him to be a part of it. I signed up for email updates from PA ABLE and watched for the start-up like a hawk. When I received the email announcing the start-up of PA ABLE, I opened the account for Andrew and had automatic deposits made to an account on a monthly basis. It has been almost one year since we started the program and he has a little over \$1,000 saved.

One of the best things about this program is the flexibility to save in a variety of ways. Saving can be done through payroll deduction, automatic deductions from checking or savings accounts, personal donations and even contributions by family and friends. There are also investment options to choose from so you can "play the stock market" or just have an "interest bearing" checking account. To me PA ABLE is a win-win situation – there is extra cash for an unforeseen expense or a way to save for something special. This could make the life of a Social Security recipient with a qualifying disability less challenging. The qualifying expenses are broad: education, housing, transportation, employment training, preventive health and wellness, to name a few. This gives me peace of mind because I am not going to live forever, and knowing there is a way to help my son, Andrew, save takes a weight off my shoulders (*big time*). The benefits are numerous when it comes to tax benefits – no worries there. The amount he can save is substantial almost like having a 401K. I am so glad this program exists and have been happy I could get the word out via Social Media and word of mouth.

My concerns for this program is that it is so new; I say this because I really just "stumbled" upon it. Anyone I have mentioned this program to had no prior knowledge of it and were thrilled to hear the news. Everyone should have the opportunity to save for their future and the disabled are no different. There should be more effort to "spread the word" about this program. Brochures should be in every Social Security and Department of Welfare office in the State of Pennsylvania. Information should be in our local, state government offices and Senior Citizen Centers. Any agency which assists people with disabilities such as Luzerne County Mental Health/Developmental Services, The ARC of Pennsylvania, Advocacy Alliance, Center for Independent Living, to name a few, should have information about the benefits PA ABLE has to offer. I, myself, would be willing to assist in "getting the word" out there, too.

Thank you for giving me the opportunity to participate in this hearing and being a voice for my son, Andrew. My own mother, who is 92, still worries about me and whether I have enough money. Therefore, PA ABLE allows me, as a Mom, to have this safety net for my son. God bless all of you and please continue these efforts to provide for the disabled of our state.

---

**Written Testimony of Caren Leonard, Easton, Pennsylvania**

Thank you for the opportunity to tell you about my family's experience with ABLE. My name is Caren Leonard and I live in Easton, Pennsylvania. Other members of my household include my husband, Peter Holderith, and our son, Julian Holderith. Our older son, Philip Holderith, lives in Allentown, Pennsylvania.

My husband and I are both sixty-seven years old. Peter is an IT specialist for a nursing home corporation. I am a former social worker and I have worked as a musician and an educator. I am employed by ProJeCt of Easton as a substitute adult literacy teacher.

Julian Holderith was born in August 1990. Within hours of his birth, my husband and I learned that not everything was right with Julian. It turned out that he had cancer and a rare birth disorder, Rubinstein-Taybi Syndrome (RTS). Individuals with RTS have pervasive cognitive/developmental disabling conditions and are subject to a broad range of possible health complications. Julian's first few years of life were a whirlwind of medical appointments and procedures, while I did my best to navigate the confusing and, often, frustrating system of county, state, and federal services set up for children with disabling conditions.

Despite all his problems, Julian was a truly delightful child. There was a serenity about him, which helped us deal with the chaos in our lives. In addition, his joy and excitement were always infectious. Over the years, many fine professionals and para-professionals have worked with Julian and we hear repeatedly how much they enjoy spending time with him. Julian's presence lights up any room he enters. Like any human being, Julian has his strengths and limitations. His verbal expressive ability is limited and he has no concept of danger. He cannot be left alone at home, nor can he leave the home unaccompanied. However, his receptive language skills are good and he reads, writes, and uses a computer. He can follow simple directions and his memory is quite good.

After graduation from high school, Julian enrolled in a local day program with Community Services Group in Bethlehem, Pennsylvania. The program offers on-site activities, occasional field trips, and the opportunity to participate in community service. Through the program, Julian volunteers for Meals on Wheels. In addition, Julian volunteers with me on a weekly basis at the Easton Public Library and, occasionally, at the community garden run by my employer.

The financial concerns of families like mine, families who have loved ones with serious disabling conditions, cannot be overstated. Families face serious financial challenges—medical, childcare costs long beyond the time typically developing children have outgrown the need for a babysitter, incontinence supplies, etc.—while, at the same time, experiencing constraints on earning ability. I was never in a position to return to full-time work after Julian's birth and even part-time and per-diem work has been challenging. However, probably the greatest worry, the cause of sleepless nights, is this: What will happen to my child when I am no longer able to care for him? My husband and I are in reasonably good health, but no one lives forever. Setting aside funds for your "special" child was, we learned, a complicated process, something that needed to be done carefully in order not to jeopardize the child's benefits.



When I first learned of the ABLE Act, I was very hopeful that this would provide an opportunity to save for Julian's future. I became rather frustrated, as the bill seemed bogged down in Congress, despite having broad, bi-partisan support. I wrote at least one letter to the editor of our local newspaper, expressing support for the bill and, if I remember correctly, a few letters to various legislators. When the ABLE Act became law, I breathed a sigh of relief, knowing that there would be a way I could make my son's future a little more secure.

Shortly after the ABLE program went into operation in Pennsylvania, I arranged for Julian to become an account owner. It was not especially difficult to set up the account and arrange for an automatic monthly deposit. My husband and I intend to do our best to deposit the maximum amount permitted to the account. Our plan is to see that funding is available for Julian's care when we are no longer able to provide it ourselves. While we know that our older son will step up to care for Julian when the need arises, the fact remains that our older son will still have to earn a living and may need to hire people to assist in caring for Julian, something for which the ABLE account can be used.

One suggestion I have regarding the ABLE program has to do with my husband's and my age, relevant to Julian's age, 27. By my calculations, based on the maximum permitted annual contribution to an individual ABLE account, it will take over thirty years to reach the current ABLE account maximum. For parents in their twenties and thirties, this may be reasonable; in our family's situation, we just have to hope to live to one hundred—possible, but, hardly a given. It might be helpful to have the option of making "catch-up" contributions as is done with some retirement savings plans. Just thought of another suggestion: Publicity! Let us get the word about ABLE out to everyone!

In closing, I would like to thank you, Senator Casey, for taking the initiative to create this valuable program and for all your hard work in shepherding the legislation through Congress. I truly believe that the ABLE plans are a win for everyone and I am proud that the State of Pennsylvania has given our nation this gift.

---

**Written Testimony of Barbara Lichtman Tayar, Huntingdon Valley, PA**

Thank you Chairman Collins, Ranking Member Casey, and the Special Committee on Aging for giving me the opportunity to present this statement to you.

My name is Barbara Lichtman Tayar and I am the mother of Estey Tayar, my 22 year old daughter who has autism. Estey's immediate family consists of myself, her 63 year old mother, her father who lives overseas and her brother who was one year older than Estey who passed away from cancer at the age of 12. Three days ago marked 11 years that he succumbed to this horrendous disease. Professionally, I mediate labor disputes. I am a federal employee, Commissioner, with the Federal Mediation and Conciliation Service. I include this information only to indicate to you that I am relatively savvy, can advocate for my daughter, and can typically be efficient in cutting through some bureaucracy. The lifelong challenges

parents or loved ones face navigating the road to supports and services for people with disabilities are very frustrating, thoroughly exhausting, and all consuming. Throughout her life, I have had to take breaks to “recharge” in order to assist her in developing into the young woman she has become. She has made many strides but is still considerably disabled.

I have been asked to specifically address our experience and thoughts regarding the ABLE account. I opened an ABLE account in Pennsylvania for Estey Tayar at the end of last year. This was just one piece of my attempt to focus on Estey’s future financial stability, especially when I am no longer on this earth to care for her and oversee her safety and security. This is the scariest thought of my life. Equally if not more so in some ways than losing my son. I do not like to make assumptions but will take the liberty here. I assume each of you who are parents have given the thought of life long stability for your own children. I also assume you know someone personally with a disability or someone with a disabled child and imagine they have expressed to you and you may even attempt to put yourself in their shoes to understand how concerning that is.

I come from parents who were both first generation Americans. My father was a bread baker, working for 50 years. My mom, after taking care of my brother and I, went to work in retail when we became a little older and could look after ourselves. I do not believe either of them ever collected unemployment or welfare and I know my brother nor I never did. My family has always been proud to have a very strong work ethic. We were taught to fend for yourself, look after your own and do what you could for others. We are “givers” rather than “takers”. Throughout her lifetime, my daughter will not be able fend for herself, look after her own (her elderly mother one day), nor assist others, for she is in need of caretakers herself. Thank goodness, she is independent in some ways but her communication abilities are severely impaired.

I am not up on the latest statistics of the number of people with autism or other disabilities or how many are unemployed or are working for minimum wage, (\$7.25 in Pennsylvania), or not much above that, but I know they are staggering. Estey is fortunate. Because of my network of family and friends who have lived in the Philadelphia area all our lives, Estey has a job. She works Monday through Friday from 9am to 3pm prepping meals for a catering business. She makes \$7.25 per hour without any benefits. No holiday pay, sick time, vacation, let alone any health care or pension opportunity. She loves her work and feels good about herself knowing she has somewhere to go every day and feels useful. I am torn between being grateful she has a job, and feeling bad that she stands on her feet all day, works hard and comes home with \$155.54 per week. Of course this is deducted from her SSI she receives, which is fine because it is important that she works for so many reasons. She is always punctual, never would tell an employer, “It’s not my job”, and actually shows up for work everyday.

The ABLE account is a way for me to put some money away for her which will not jeopardize her entitlement to SSI or other needs based services. She will never be in a position to be able to pay rent, buy food, pay for health care or any of the other necessities in life we all take for granted. I did not mention vacations, clothing, or entertainment since that would be nowhere

in the picture for her in her position. \$100,000 is the current ABLE limit without jeopardizing her SSI. \$100,000 will not go far over her lifetime. At 22, I hope she has a long, healthy, content life ahead of her. At 64 next week, my time to look after her is much shorter. I hope this Committee gives consideration not only to continue the ability through the ABLE account or other means to put some assets aside for a population that is extremely vulnerable and limited in their ability to provide financial stability for themselves. I would also ask that you consider raising that limit without jeopardizing other needs based entitlements.

I have attempted to limit my remarks to this narrow subject of the value of the ABLE account. It is important. However, there are so many challenges facing all of us as we age but especially this vulnerable population of people with autism or other disabilities. As the Special Committee on Aging, I commend you for your attempts to address the issues that face us all whether our own or as fellow Americans. I am honored to have the opportunity to be heard by each of you. I speak to you from my heart and soul and would welcome and make myself available anytime to speak with any of you regarding all the challenges as the disabled population and their families' age.

Thank you and God bless you all.

---

**Written Testimony of Rachel Lindstrom, Roxborough Area of Philadelphia, PA**

My name is Rachel Lindstrom. I am 67 years old and I live in the Roxborough area of Philadelphia, PA. My daughter, Mara Lindstrom, is disabled and I am her Social Security disability benefits representative payee. Mara is the owner of an ABLE account that I opened for her so that she can save money for future needs that Medicare does not cover.

By the time Mara was approved for SSDI benefits, she was due retroactive benefits, which she received in a lump sum near the end of 2017. I did not know about the ABLE program until May 2018, and as soon as I learned of it, I opened an ABLE account for her. In doing so, I was trying to preserve her eligibility for additional medical assistance; however, the lump sum she received was more than twice the annual contribution limit for ABLE accounts. Unfortunately, this annual limit means that she still fails to qualify for services such as Medicaid or Extra Help through Medicare because even after opening the ABLE account, she exceeds the \$2,000 annual limit for such benefits in non-ABLE bank account balances/cash on hand. The maximum annual contribution limit will mean that she will still have too much cash on hand for at least two more years.

So, while I am grateful that she now has an investment account for her future needs, it has come at the expense of disqualifying her for needed services now. It would be helpful if the annual maximum contribution could be waived for retroactive lump sum payments from Social Security Disability benefits since this situation will only arise once for a recipient.

---

**Written Testimony of Richard C. Mariette**

Greetings. My name is Richard Mariette, I am a life-long resident of Pennsylvania, born and raised in Northeastern Pennsylvania. During the last 32 years, have been a resident of the Philadelphia suburbs and the City of Philadelphia. Thank you, Chairman Collins, Ranking Member Casey and the Special Committee on Aging for providing this opportunity to submit commentary on PA ABLÉ accounts and my experience as a brother to, and caregiver and fiduciary for my special-needs sister.

My sister, Diane Mariette, recently turned 50 in April. Having been born with Down syndrome, Diane has persevered with a positive spirit and has lived a fulfilling life, exploring and testing the limits of her full potential. To an observer, Diane's life may perhaps appear to be one of challenge, adversity and some would say, endless struggle.

It is true that her individual struggles to work through painful limitations are real and Diane's best effort to thrive in a world that may not care, or have the time or the ability to understand her reality and needs, is an immeasurable challenge.

About Diane's needs, she does not have the capacity to provide for herself or act on her behalf. She has chronic medical conditions and challenges that are common to similarly situated individuals and requires care, significant resources, support, advocacy and a fiduciary. As her brother and power of attorney, I have worked strenuously to seek and locate resources and care for her. This is a role that has grown over time; first with the sudden loss of our father in 1988 and during our mother's valiant fight against dementia, and other challenges of aging since 2009. Our mother will turn 94 in August and has lived in a wonderful elder care community since 2014, but has lost her ability to care for herself or Diane in recent years.

During Diane's life, our parents Jean-Claude and Rose, dedicated their lives to the unique challenges that they embraced in 1968 when Diane was born, at a time when understanding, resources and support were comparatively scarce. They selflessly devoted their energy to our well-being, but certainly worked with endless love and care to raise Diane with remarkable expectations and outcomes. Our parents could not have done more.

Fortunately, they discovered public resources over time and especially the Day Development Program in Kingston, Pennsylvania, administered by the Luzerne-Wyoming Counties Mental Health and Developmental Services. Diane has attended this program for decades and has had the good fortune of being able to attend this wonderful program and to receive transportation to and from Day Development.

As mentioned, Diane's needs are extensive, and thankfully, benefits from the federal and Pennsylvania state level, that are administered at the county level, are vital to Diane and certainly others. Safeguarding and conserving resources for special-needs individuals is essential and just last week, a truly special person, who is a trusted family advisor introduced the benefits of a PA ABLÉ account to us. Achieving a Better Life Experience (ABLE) is a program introduced in Pennsylvania in 2017 because of an effort led by Senator Casey. ABLÉ accounts reward initiative and family responsibility and provide people with disabilities a way to be more financially independent. ABLÉ accounts also protect eligibility for means-tested federal and other benefits, alleviating individuals from having to choose between services and benefits. We are thankful for the efforts of Senator Casey and the U.S. Senate Special Committee on Aging.

We are fortunate and grateful to live in a country that is increasingly mindful of the needs of individuals with disabilities and special needs and a country that is devoting increasing effort to planning for the needs of aging citizens.

---

#### **Written Testimony of Mary Catherine Sabatos**

My name is Mary Catherine Sabatos. I am the sister of Joseph Sabatos, a man born with Down syndrome. Joseph is one of seven siblings, and he is the youngest in our family at the age of 56. After my brother was born, my parents were warned not to expect a long life for my brother due to medical complications at birth and the nature of Down syndrome individuals in general. Medical advances, educational opportunities and a loving family unit made it possible for my brother to live and thrive. As a young adult, he began to live in a group home where he socialized with other developmentally disabled adults. He went to dances and attended a day program that kept him engaged. His favorite hobbies were doing word search crossword puzzles, reading the front page headlines of newspapers and copying them in notebooks, and doing subtraction and addition problems. He also loved music, country and polka, and James Bond movies. He knew and collected every Bond film! Everyone in the family was happy and grateful that my brother had his own life and his own interests.

As my brother aged, his physical and mental status changed dramatically. Although he was in his early 50's his brain had aged more like a 75-80 year old. He was no longer as alert; he stopped enjoying the things he loved for so long, had difficulty in family gatherings getting very agitated and confused. Dementia had become part of his world and ours. His life slowed down and changes needed to be made.

Approximately two years ago, my brother's life changed dramatically. He was hospitalized for sepsis, and pneumonia. He was critically ill and nearly died. Once he left the hospital, he was transferred to a nursing home where no one had expertise in working with developmentally disabled adults. Fortunately, his social worker, Sharon McGraw, found an opening with Life Steps, and a new group home and life for my brother opened up in Pittsburgh, Pennsylvania. At this same time, we learned about the ABLE program through social media, and we explored the state of Pennsylvania's ABLE program. We realized this was a perfect solution to my brother's problem of sometimes having too much in his saving account, and a way for us to save money for him for future needs. We realized that he would need to be able to have funds set aside to help him as his dementia progressed. Specialized equipment, such as a motorized chair that allowed him to transfer from sitting to standing easily, and a bed that did the same would make his life less stressful. Therapeutic services, such as music therapy, that could help him stay engaged would be important in the near future.

As it turned out the application for PA ABLE was fairly easy and straightforward. Almost everything could be done online. We needed to update our Power of Attorney to less than 6 months old and we arranged for a checking account to be opened in case he needed money quickly. This account has eliminated financial concerns we have had in the past and given us an option that allows us to be able to make decisions looking toward the future. Who knows? My brother might outlive all his siblings. Knowing this and that he has money in the bank when he needs it is one less thing we need to worry about.

---

**Written Testimony of Gerald and Marion Senese, Sayre, PA**

My wife and I are both disabled. I was permanently injured in 1988, never able to work again. My wife became paralyzed 10 years ago with late stage Neurological Lyme Disease. Only one person per household can collect disability benefits. This made this near impossible to exist financially and especially medically if it were not for the PA ABLE Program.

I followed with great interest the other states ABLE program and was hopeful PA would adopt a similar program. I was very happy and relieved when I received notification that I was eligible. This program has allowed friends and family to assist us with the many medical expenses that the insurance does not cover without sacrificing our PA state benefits. Thank you so very much for the advancement and continuation of this program. It has saved our lives. My only concern is that many banks have no idea this program exists. When I went to open the account, I had to bring all the info I had and they had to research it out for themselves as well as they had no idea about it. Our local banks now know because I had to educate them. My concern is that the maximum allowable per year for the program will not increase with the rate of inflation, therefore, making it difficult once again for us to survive.

**Written Testimony of Pamela Shonk, Mountain Top, PA**

My name is Pamela Shonk. I am 62 years of age and live in Wilkes-Barre area. I am a registered nurse and work from home doing medical research. My husband, John Shonk, is a physician specializing in Physical Medicine and Rehabilitation.

I am the mother of a daughter, Gailey, who is a PA ABLE account holder. She is 18 years old, who is on the autism spectrum (Asperger's with intellectual disabilities), as well as, Type I diabetes. I opened the account for her to give her economic stability. She will be able to control the account when she is 21 years of age, but the account ensures that only so much is dispensed for appropriate items. This protects her from losing SSI benefits and as far as I know, no other fund has this ability.

PA ABLE only allows a certain amount to be donated to the account. Gailey, also, has a living trust, so that a larger amount of money is available to the trustees for her care, but is not under her direct control. This will safeguard her from anyone trying to take advantage of her. We anticipate that she will inherit a substantial amount of money that we want protect for her future needs. I wish that the PA ABLE account did not have a limit of \$14,000 a year that can be donated into the account per year.

Medication (insulin) and the other equipment for Diabetes Type I are expensive even with good health insurance. For insulin, we pay a medication copay of \$153 for three bottles, which lasts approximately one and half months, plus the copays for the equipment for insulin pump and sensor monitoring. Also, since Diabetes is a chronic disease and is the underlying cause to other diseases, this will lead Gailey to other medical problems; therefore, the medical costs will only increase as she ages.

The statistics show that 80% of adults with Autism are NOT employed, which makes the PA ABLE account and the living trust very important for Gailey's economic security.

Since I am 62 and my husband is 61, it is very important to us that Gailey is economically stable, but also Independent so that when we die, she will be able to care for her living and medical needs. We feel that the PA ABLE account is an essential part of her economic well-being.

Written Testimony  
Provided by

**Joe Joyce, Chair**

On behalf of  
**Autism Society of America**

For the  
United States Senate Aging Committee Hearing  
July 18, 2018

**“Supporting Economic Stability and Self-Sufficiency as  
Americans with Disabilities and their Families Age”**

Thank you Chairwoman Collins, Ranking Member Casey and other Members of the Aging Subcommittee for holding this important hearing and accepting this written testimony. I am submitting this testimony on behalf of the Autism Society of America; however, I will also be sharing my personal story as a father of two adult sons with developmental disabilities.

The Autism Society of America just held its 50<sup>th</sup> annual conference and Hill Day last week with almost 400 participants. Our grassroots organization was established in 1965 by parents caring for what was then, an unusual disability called “autism.” Not much was known about the disability back then. What these parents shared was the desire to keep their children with significant disabilities at home, not in an institution. They shared information and advocated for services to help them raise their loved ones at home along with their siblings. The Autism Society continues this mission.

I am the father of two individuals with significant functional limitations: David, age 19, has autism and Matt, 22, has Down syndrome; both have intellectual disabilities and developmental disabilities. Developmental disabilities are defined in law as physical or mental impairments that begin before age 22, are likely to continue indefinitely, and result in substantial functional limitations in at least three major areas of self-care. In spite of these limitations, both of our boys are loved and valued members of our family and community. David and Matt are handsome, loving, thoughtful, caring individuals with so much to contribute to our family. We have no regrets regarding the decision to raise them at home. My wife, Elise, and I have been caring for them and our beloved daughter, Tara, their whole lives.

We know that David and Matt will not be able to care for themselves without significant supports. We worry about what will happen to them when we are no longer here to take care of their every need.

During their childhood, we just went day to day surviving. It is hard to find time to plan for their future. As our children are transitioning to adulthood, we are now forced to think about where they will live, how they will be able to find work, and how they will be supported after we are gone.

Elise and I purchased a four-bedroom home in April 2017 to be used as a group home for our son David and other individuals. To this date, David has not been able to move into the home, and the house sits unoccupied. David has severe self-injurious behaviors and is non-verbal. We have been unable to find a licensed agency to operate the home. All agencies have declined due to inadequate provider rates to serve high-risk residents.

We are fortunate to have some resources for this planning but millions of individuals with disabilities and their families depend on a wide variety of public benefits for income, health care, food and housing assistance. Eligibility for these public benefits (SSI, SNAP, Medicaid) require meeting a means or resource test that limits eligibility to individuals to report more than \$2,000 in cash savings, retirement funds and other items of significant value. To remain eligible for these public benefits, an individual must remain poor.

Thanks to Congress, the ABLE Act recognizes the extra and significant costs of living with a disability, and these individuals will be able to save. These costs include making our house accessible, accessible transportation, trained respite care, personal assistance services, assistive technology, health and behavioral health care not covered by insurance. I am looking into opening one of these accounts right now. Congress must also be aware that many individuals and families will not have the extra money to put into these ABLE accounts. In addition, those individuals diagnosed after the age 26 are not eligible for ABLE accounts.

Many individuals with autism and other developmental disabilities are able and want to work. However, they are prevented from making enough money to be self-sufficient for fear of losing the small amount of income supports they receive through Social Security. Due to the so-called substantial gainful activity level (SGA), individuals cannot make more than \$1,180 per month. This is not enough to be self-sufficient. More importantly, they do not dare risking losing health care through Medicaid.

People with disabilities also deserve to make at least minimum wage or above. States need assistance moving away from sheltered workshops to modern models of matching the needs of employers to the abilities and desires of individuals with disabilities. For those who choose not to work or for whom their disabilities make it too difficult to maintain work, there must be opportunities for meaningful activities during the day. Eligibility for Medicaid is tied to Social Security. Medicaid not only provides the comprehensive health care many people with developmental disabilities need (care often not provided by many private insurers), it also provides long-term services and supports many individuals need to continue to be able to live and work in the



community. These include supported employment services, behavioral health, and habilitation. Habilitation services help a person learn or improve skills and functioning for daily living (such as physical therapy or training to use public transportation). Unfortunately, these home and community-based Medicaid services are optional for states and there are long waiting lists for them. Home and community based services should be mandatory. Waivers should be required for institutions.

In Pennsylvania, there are 42,820 people over the age of 60 still caring for their family member with developmental disabilities (Braddock, *State of the States in Developmental Disabilities*). There are 52,139 caregivers between 41 and 59. These ranges includes my wife, Elise and myself. We need family supports, like respite care, so that we can take a break, have a date with each other, go on a doctor visit, or to the grocery store. We are also very worried about who will care for our sons when we are gone. We are literally afraid to die. Where will they live? Will they be free from harm? Will they still be able to do the things they love to do, like play baseball, visit their friends, and choose their own meals? Many parents share these worries.

In all the years I have been involved in the Autism Society, I have become more worried than ever about the growing number of people with autism and other developmental disabilities coupled with the number of people who are aging and needing long-term care. Congress must find the political will to help states provide these services. Please do not turn your backs on people with disabilities and those of us who are aging. Following are just some of the recommendations the Autism Society has for Congress that might help.

Regarding helping people to work, we recommend that Congress:

- Double the Work Opportunity Tax Credit (WOTC) and the Business Tax Credit to incentive businesses to hire people with disabilities.
- Double the Architectural and Transportation Barrier Removal deduction to help remove access barriers.
- Double the Disability Access Tax Credit for small businesses to provide incentives to businesses to remove barriers.
- Address the constraints put on people with disabilities by having the limit for substantial gainful activity as such a low level (\$1,970/month for those who are blind and \$1,180 for all others with disabilities) that it discourages people to work, to accept promotions, and to start their own businesses.
- Phase out use of subminimum wage certificates (under the Fair Labor Standards Act) while helping states build capacity to provide competitive integrated employment
- Provide increased Medicaid matching rates to states providing competitive integrated employment to individuals with developmental disabilities.

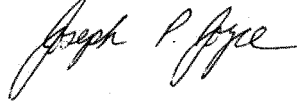
- Increase the supported employment program and provide demonstrations to increase customized employment best practices.
- Mandate the state Medicaid buy-in program so that people can work and still get health care (now an option for states through Social Security Section 1619(b)).
- Support the ABLE Age Adjustment Act of 2017 (H.R. 1874; S. 817) so that more people with disabilities can save for disability-related needs that may lead to employment

Regarding helping people find home and community-based services, the Autism Society recommends Congress:

- Oppose efforts to cut, cap or eliminate the individual entitlement to Medicaid.
- Oppose work requirements in the Medicaid program.
- Reduce the bias in Medicaid for institutional services and significantly increase the investment in home and community-based services and supports.
- Support the Disability Integration Act and other proposals that support the right to services in the community.
- Create a national long-term care system outside of Medicaid.
- Provide funding for new demonstrations for states to test community supported living arrangements to help provide housing options in the community for people with developmental disabilities and those who are aging.

The Autism Society has numerous professionals, family members, and individuals on the autism spectrum with expertise and willingness to help.

Sincerely,



Joe Joyce  
Chair, Autism Society