# Written testimony of Elizabeth A. Bechtel for the July 18, 2018 hearing of the U.S. Senate Special Committee on Aging, addressing the economic health of people with disabilities

To: Sen. Casey and Sen. Collins
From: Elizabeth A. Bechtel
Date: July 10, 2018
Re: PA ABLE

This is written testimony for the July 18th hearing of the Special Committee on Aging addressing the economic health of people with disabilities.

My name is Elizabeth A. Bechtel. I live at Boalsburg, PA 16827. (My mailing address is , Boalsburg PA 16827.) 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 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 is a remarkable program that 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.

There are a few enhancements that 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
- 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.

Sincerely,

Elizabeth
Bechtel

# Written testimony of Nancy Briski for the July 18, 2018 hearing of the U.S. Senate Special Committee on Aging, addressing the economic health of people with disabilities

Dear Senator Casey,

My name is Nancy Briski and my address is Allison Park, Pa 15101. My email address is This is written testimony for the July 18th hearing of the Special Committee on Aging which is addressing the economic health of people with disabilities.

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 $2000 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 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 and 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 it's eligibility requirements so as to not penalize our most vulnerable citizens. Thank you for giving me this opportunity to speak.

Sincerely,

Nancy Briski

Allison Park, PA 15101

# Written testimony of Helena Chojenski for the July 18, 2018 hearing of the U.S. Senate Special Committee on Aging, addressing the economic health of people with disabilities

My name is Helena Chojenski. I can be contacted at

This is my written testimony for the July 18th hearing of the Special Committee on Aging addressing the economic health of people with disabilities.

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 I and my relatives 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 for the
# July 18, 2018 hearing of the
# U.S. Senate Special Committee on Aging, addressing
# the economic health of people with disabilities

Dear Senator Casey:

This is written testimony for the July 18th hearing of the Special Committee on Ageing addressing the economic health of people with disabilities. 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 got me ultimately 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 suggested and have 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 didn’t complete the Chemistry major because in early 2012 my disability struck again and I suffered a wild bout of mania. That’s 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. Also, 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 of 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 of credit cards to make ends meet. But this was not a terrible time for me, because I felt inspired, nay, 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. Midst 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 year-end 2017 with a fair market value of $849.34.

Johnny and I got married November 2nd, 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's 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 14th, 2018. My new job has a default, matching 401 (k) that I'm 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 26th, 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! Also, thinking of ABLE Account as a conceptual investment vehicle for support for people whose disabilities prove more extensive to treat than mine, I have hoped my participation with it strengthens it for others.

Thank you for reading my testimony.

Stephen Foery

July 8th, 2018

# Written testimony of Annette Holland for the July 18, 2018 hearing of the U.S. Senate Special Committee on Aging, addressing the economic health of people with disabilities

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 and had to keep my savings BALANCE below $2000. 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 PAABLE 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 PAABLE ACCOUNT.

Annette Holland

# Written testimony of Keith Kerns for the July 18, 2018 hearing of the U.S. Senate Special Committee on Aging, addressing the economic health of people with disabilities

Keith Kerns 07/13/2018
Maria Kerns

Harrisburg-Steelton, PA 17113-2602
Phone
Email

Testimony for the July 18, 2018 hearing of the Special Committee on Aging

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 inutero when his mother was in a car accident in Texas when 8 months pregnant. He had a trust in Texas as a result of a settlement of a law suit. 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 and arrested and imprisoned for Felony Child Endangerment. We took Skylar from her and hired an attorney getting legal custody in May 2014.

The ABLE account is in Skylar's name and I (Keith Kerns) administer it is well as his survivor benefit.

Maria is a retired teacher and I am retired from The State of Pennsylvania. We had a real 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 $2000 limit at that point. However, having to simply spend Skylar's money to keep his benefits made no sense to me.

We got another appointment with Social Security and discovered that the settlement for the accident inutero that was in a Trust in Texas disqualified him. In the meantime, we were told by Vista School employees about the ABLE 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 ABLE 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 GOD send. 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 some special item for him. For example, we recently purchased a $2,000 special needs stroller with ABLE funds so when we take him to places like Hershey Park he does not have to walk all day as 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 for the July 18, 2018 hearing of the U.S. Senate Special Committee on Aging, addressing the economic health of people with disabilities

July 13, 2018

RE: PA ABLE Account Participation

Dear Senator Casey and Members of the Special Committee on Aging:

My name is Mary Ann T. Kline and I am the mother of PA ABLE account holder Andrew C. Kiss. I am providing written testimony for the July 18th hearing of the Special Committee on Aging addressing the economic health of people with disabilities. My son, Andrew, is 26 yrs old and was diagnosed with an Autism Spectrum Disorder classified as Asperger's when he was about 10 yrs 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 3 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 now been almost one year since we started the program and he now 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's 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'm not going to live forever, and knowing there's 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'm 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's so new; I say this because I really just "stumbled" upon it. Anyone I've 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. So, 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.

Sincerely,

Mary Ann T. Kline

Hazle Township, PA 18202

# Written testimony of Caren Leonard for the July 18, 2018 hearing of the U.S. Senate Special Committee on Aging, addressing the economic health of people with disabilities

Dear Senator Casey,

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. I can be contacted at Other members of my household include my husband, Peter Holderith, and our son, Julian Holderith. Our older son, Philip Holderith, lives in Allentown, Pennsylvania.

This written testimony is being provided for the July 18th hearing of the Special Committee on Aging addressing the economic health of people with disabilities.

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 also 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 everything was not 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. And his joy and excitement were always infectious. Over the years, many fine professionals and para-professionals have worked with Julian and we hear over and over 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. But 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. But, 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 (67), 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's 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.

Sincerely,
Caren Leonard

# Written testimony of Barbara Lichtman Tayar for the
# July 18, 2018 hearing of the
# U.S. Senate Special Committee on Aging, addressing
# the economic health of people with disabilities

Thank you to 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 Commissioner with the Federal Mediation and Conciliation Service, a federal employee. 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 don't 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 1st generation Americans. My father was a bread baker, working for 50 years and 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 don't 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". My daughter cannot fend for herself throughout her lifetime, 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 didn't 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 life time. 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 G-d bless you all.

Barbara Lichtman

Huntingdon Valley, PA  19006

# Written testimony of Rachel Lindstrom for the July 18, 2018 hearing of the U.S. Senate Special Committee on Aging, addressing the economic health of people with disabilities

This is my testimony for the July 18, 2018, Special Committee on Aging's hearing addressing the economic health of people with disabilities.

My name is Rachel Lindstrom (email: . I'm 67 years old and I live in the Roxborough area of Philadelphia, PA. I am the mother of, and Social Security Disability benefits Representative Payee for, my disabled daughter, Mara Lindstrom, who 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 didn't know about the ABLE program until May of 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 nonABLE 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.

Thank you for letting me tell you about our situation.

# Written testimony of Richard C. Mariette for the July 18, 2018 hearing of the U.S. Senate Special Committee on Aging, addressing the economic health of people with disabilities

Greetings. My name is Richard Mariette, I am a life-long resident of Pennsylvania, born and raised in Northeastern Pennsylvania and 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 ABLE 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 ABLE 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. ABLE accounts reward initiative and family responsibility and provide people with disabilities a way to be more financially independent. ABLE 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.

Thank you for the opportunity to provide these comments.

Respectfully,

Richard C. Mariette

# Written testimony of Mary Catherine Sabatos for the July 18, 2018 hearing of the U.S. Senate Special Committee on Aging, addressing the economic health of people with disabilities

The Honorable Senator Bob Casey
Special Committee on the Aging

My name is Mary Catherine Sabatos, I am the sister of Joseph Sabatos, a man born with Down Syndrome. Joseph is one of 7 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. Though 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, he 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 2 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.

Contact information:

# Written testimony of Gerald & Marion Senese for the July 18, 2018 hearing of the U.S. Senate Special Committee on Aging, addressing the economic health of people with disabilities

Gerald & Marion Senese

Sayre, PA 18840

To Whom It May Concern:

As disabled husband and wife, we are writing this testimony for the July 18th hearing of the Special Committee on Aging addressing the economic health of people with disabilities. I was injured in 1988 permanently, never able to work again. My wife became paralyzed 10 years ago with Late Stage Neurological Lyme Disease. Only 1 person per household can collect disability benefits. This made this near impossible to exist financially & 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 w/o 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 and 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.

Thank you for listening to my concerns.

Most Sincerely Yours,

Gerald M. Senese, Account Holder

Sayre, PA 18840

# Written testimony of Pamela Shonk for the July 18, 2018 hearing of the U.S. Senate Special Committee on Aging, addressing the economic health of people with disabilities

Pamela Shonk

Mountain Top, PA  18707

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 3 bottles, which lasts approximately 1 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.