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SAVING FOR AN UNCERTAIN FUTURE: HOW THE ABLE ACT CAN HELP PEOPLE WITH DISABILITIES AND THEIR FAMILIES

HEARING

BEFORE THE

SUBCOMMITTEE ON TAXATION AND IRS OVERSIGHT

OF THE

COMMITTEE ON FINANCE

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SAVING FOR AN UNCERTAIN FUTURE: HOW THE ABLE ACT CAN HELP PEOPLE WITH DISABILITIES AND THEIR FAMILIES

WEDNESDAY, JULY 23, 2014

U.S. SENATE,
SUBCOMMITTEE ON TAXATION AND IRS OVERSIGHT,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 10:08 a.m., in room SD–215, Dirksen Senate Office Building, Hon. Robert P. Casey, Jr. (chairman of the subcommittee) presiding.

Present: Senators Enzi, Thune, and Burr.

Also present: Democratic Staff: Kara Getz, Senior Tax Counsel; Jocelyn Moore, Deputy Staff Director; and Tiffany Smith, Senior Tax Counsel.

OPENING STATEMENT OF HON. ROBERT P. CASEY, JR., A U.S. SENATOR FROM PENNSYLVANIA, CHAIRMAN, SUBCOMMITTEE ON TAXATION AND IRS OVERSIGHT, COMMITTEE ON FINANCE

Senator CASEY. This hearing will come to order. I am grateful for everyone's presence here.

This morning we convene the Finance Committee Subcommittee on Taxation and IRS Oversight to discuss an important topic: how we can help individuals with disabilities and their families save for the future.

I would like to thank Chairman Wyden and Ranking Member Hatch for this opportunity to hold the hearing of our subcommittee. I want to thank our ranking member on the subcommittee, Senator Enzi from Wyoming, for joining me today. He will be here shortly.

I really want to thank Senator Burr from North Carolina, a tireless, tireless advocate for this legislation, and I want to thank him for his efforts to create a more sound future for those living with disabilities through the ABLE Act. Senator, I do want to thank you for your work. I am grateful that we can work together on this.

Right now the tax code provides incentives for Americans to save for important priorities such as retirement or college through tax-advantaged savings accounts. However, those with disabilities are not afforded the same opportunity to save for their future. In fact, many adults with disabilities cannot save money to cover costs related to their disability without becoming ineligible for various programs, like Social Security or Disability Insurance or Medicaid—whatever it is that provides a necessary lifeline to so many who are in need. This dynamic forces individuals with disabilities to rely upon their family or community, but this support is often not enough to cover their long-term needs.

Take the experience of one of our witnesses today, Sara Wolff, from Lackawanna County, PA. We happen to live in the same county. I have known her for quite a while. But Sara is not only here to testify, she is also here to tell us about her life, a life where she is holding down not one, but two jobs, but she has to plan carefully to ensure that she never amasses more than $2,000 in assets or she will lose critical benefits.

She should not have to make those kinds of plans. She should be given the freedom to make other plans for her future and not have to worry about making too much money in a particular time frame.

This situation is, in a word, unacceptable in the United States of America, and Congress can and should help by doing something about it. The ABLE Act gives us that opportunity. Individuals with disabilities should be able to save for their future costs on an even playing field with other citizens across the country.

The Act would fix this unfair dynamic by creating tax-free savings accounts for individuals with disabilities. Specifically, it would build on the popular section 529 college savings account program to allow families who have a loved one with a disability to similarly save tax-free for qualified disability expenses.

Beneficiaries would be able to make tax-free withdrawals from their ABLE accounts to cover basic needs like education, housing, transportation, and health care. Benefits provided through private insurance, the Medicaid program, the beneficiary's employer, or other sources would be supplemented, not supplanted by the legislation.

The ABLE Act is an affirmation that people with disabilities have great ability, great ability to live a life full of opportunity and lead a life full of achievement and success. Today's hearing will address the need for ABLE accounts from the perspective of individuals living with disabilities, advocates who are here with us today, lawmakers, and, as well, financial planners. And I left out families, and we certainly include them in that.

Through the testimony of our witnesses, we will be able to highlight the challenges individuals and families face planning for the future and the benefits and drawbacks of current savings tools that are available, and, finally, how ABLE accounts can provide an additional tool for those who are in need.

It is my hope that the record we build today will pave the way to passage of the ABLE Act, which enjoys wide bipartisan support in both houses of Congress. In the Senate, it has 75 cosponsors, and in the House 366, and we are still counting both numbers. No other bill in Congress has this level of bipartisan and bicameral support. This level of support is a testament to the hard work of families and other disability advocates, many of whom are here with us today. If they are not here, we thank them from afar.

This bipartisan support also reflects the importance of what the ABLE Act does for individuals with disabilities, as well as their families. We want all 535 members of Congress behind this important legislation. We need to build on our momentum in order to get the bill passed when we return from the August recess.

So I want to thank everyone for being here.

[The prepared statement of Senator Casey appears in the appendix.]

Senator CASEY. I now turn to our ranking member, Senator Enzi.

STATEMENT OF HON. MICHAEL B. ENZI, A U.S. SENATOR FROM WYOMING

Senator ENZI. Thank you, Mr. Chairman. Thank you for holding this hearing on Achieving a Better Life Experience, ABLE. We do these acronyms all the time, but this one is a very good one. ABLE—Achieving a Better Life Experience. I appreciate having this opportunity to take a closer look at how this legislation can help individuals with disabilities and their families live a more fulfilling and rewarding life and chart a more certain future.

I am looking forward to the open discussion about the merits of this bill, and I feel very privileged to be sitting between the two authors of the bill. You have done a marvelous job on this bill. And I know that Senator Burr has probably been involved in more detailed bills than anybody whom I know of in the Senate and has an uncanny ability to work them through to completion in both the House and the Senate, relying on some of his friendships from his House days there. But he is willing to take on some incredibly difficult bills. I do not think this is the most difficult bill you have taken on, but it is the most impressive on cosponsors that I have seen. To have 74 Senators signed onto a bill, that is more than bipartisan. That is outstanding around here, and it is a credit to both of you to have been able to do that. Good teamwork.

Mr. Chairman, history has taught us that individuals with disabilities can flourish with the help of their families and a supportive community. Disabilities that were once thought to be disqualifying and limiting in terms of an individual's ability to express themselves are now seen as challenges that can be overcome. Today, those living with disabilities have shown they can contribute in meaningful ways to our culture, the arts, our business community, and society at large. The success and flourishing of individuals within our communities makes our society more inclusive and gives everyone an opportunity to thrive and pursue whatever path they choose to follow to their ultimate happiness and fulfillment.

One of the bold statements made by our founding fathers as they worked together to create our Nation was their recognition of our inherent rights to life, liberty, and the pursuit of happiness. Few countries can boast of having been created with an eye toward that kind of freedom of expression. The legislation we are discussing today takes another step forward in the effort to make the promise of the Declaration of Independence ring true for all of us.

Mr. Chairman, if we walked over to the Capitol Visitors Center, we would see several poignant illustrations of this. One of the most well-known and best-loved examples of what is possible for those living with disabilities to achieve is seen in the life of Helen Keller, one of the newer statues over there. She was the famed author and political activist of the early 20th century. She was deaf, blind, and mute as a result of an early childhood disease. I hope all of you will take the time to look at the profile of this great person and think about how this bill can affect others in a similar way.

The ABLE Act would take a small step in helping disabled individuals support themselves, pursue their dreams, and put themselves in a place of greater financial security. It would allow them and their families to open tax-exempt accounts so that they can plan how best to use their own funds to cover living expenses.

In our economy, many families are very familiar with the challenge of saving for the future and the needs of their children. A family with a disabled individual faces even more unique emotional and financial obstacles. The ABLE Act would help these families meet these challenges, whether it is paying for specialized care or a more individualized education, to maintain their health and their independence, or provide for a better quality of life.

I have long been a supporter of enabling families and communities to meet the needs of the disabled. A few years ago, I introduced legislation to expand and revitalize the two main Federal employment and training programs for persons with significant disabilities, paving the way to create more and better jobs and restore accountability to prevent waste, fraud, and abuse.

In my own State of Wyoming, Alees Rogers in Uinta County, WY has been helped by her community. She has a developmental disability, and, with assistance for housing and other care, she was able to take a job after graduating from high school at First Bank, where she does a marvelous job. She also lives independently in her own apartment. The ABLE Act could help her to accomplish even more as she continues to plan for her future.

Wyoming has also developed an innovative college program called the Wyoming Institute for Disabilities, WIND, to help individuals with developmental disabilities, their families, professionals, and University of Wyoming students through education, training, community services, and early intervention. These types of services, combined with the ABLE Act, strengthen the opportunities for individuals with disabilities to grow, achieve, and succeed.

I do not think there was ever a more well-known or better dreamer than Walt Disney. He knew a thing or two about how to make the impossible a reality. He once said, “If you can dream it, you can live it.” I thank Senators Casey and Burr for dreaming this, and all of the people who will be helped by it for being big dreamers. Let us help more of the disabled individuals and their families do exactly that. Let us work together with them to take their dreams from the drawing board to reality by offering the support they need to make them happen.

While it is true that the initial discovery of an obstacle or a limitation can often be dispiriting or discouraging, when our families and communities circle around those facing such challenges, we can help them to rise above them and succeed beyond anything they could ever have imagined. The ABLE Act will help to make that happen by providing more financial stability so that we can all chase after our dreams and fulfill our founding fathers’ promise of the pursuit of happiness. That is why this legislation has found overwhelming support—74 members of the Senate, 366 members of the House.

I welcome our witnesses today. I appreciate their taking the time to join us for this important discussion. I look forward to their testimony.

Again, I am privileged to sit between the two people who came up with this bill. I thank you, Mr. Chairman, and would hope that we have time for Senator Burr to make a few comments.

Senator CASEY. Senator Enzi, thank you very much for your opening remarks. I am grateful for your work as well.

[The prepared statement of Senator Enzi appears in the appendix.]

Senator CASEY. Senator Burr?

OPENING STATEMENT OF HON. RICHARD BURR, A U.S. SENATOR FROM NORTH CAROLINA

Senator BURR. Chairman Casey and Ranking Member Enzi, thank you for scheduling this hearing, and thank you for allowing me the opportunity for some time to speak.

Let me say, Bob, you are a tremendous partner. We have done a number of things together, some easier than this, some that went a lot faster, but none more important than the legislation we are here to receive testimony on today.

I want to particularly thank both of you, but also Cathy McMorris Rodgers, Ander Crenshaw, Chris Van Hollen, and Pete Sessions, partners on the other side of the Hill, who have shown unbelievable passion at resolving what I think is a common-sense legislative approach.

When Mike Enzi talks about 74 cosponsors, I do not think it has ever happened since I have been here. But while we should be jubilant with the support, I sit here thinking, what is wrong with these other 26? [Laughter.] Where have we failed? Hopefully, today will be the culmination of, Bob, us getting the rest of them.

I think it has already been said that the ABLE Act enjoys this unprecedented bipartisan support, with over three-quarters of Congress now putting their names on the bill as cosponsors, and we ought to vote on it today. Unfortunately, we cannot.

It is hard for me to find a reason why anyone would want to get in the way of this bill, because it allows parents of disabled children the opportunity to save their own money for their child's future and to give that child a shot at financial independence.

As a father, I know that a piece of the American dream—no, let me say, the American dream is a parent's ability to make sure that their children are taken care of, to make sure that they are self-sufficient, not just financially, but through what we teach them.

I heard what Mike Enzi said about Helen Keller. Helen Keller was stopped by a reporter one day and the question was this: "Can you think of anything worse in life than to lose your sight?" And she paused for a moment, and she said, "Yes. To have my sight and lose my vision."

Now, we might talk about this being a dream. This is a vision. It is a vision of parents of affected children. It is a vision of this country that we should empower every family to have the capabilities to take care of the next generation, and Helen Keller is a reminder that we cannot lose what the vision is of what we are trying to accomplish.

So I hope, Mr. Chairman, that the ABLE Act does not get lost in the shuffle. It is unfortunate, but in Washington we spend most of our time arguing about issues that divide us. For Heaven's sake, let us pass a bill that we all support, that we all know is sound policy, and that we all believe will make a world of difference to families who are simply asking for the hope and the dream and the vision.

We have been working together in good faith with all stakeholders, and I look around this room, and a few people have not been in the meetings to improve and perfect this bill for 8 years. If there is one thing we can be accused of, it is persistence. We have not gone away.

So let us pass the ABLE Act, and let us do it now.

Also, Mr. Chairman, I want to briefly welcome my fellow North Carolinian, Robert D'Amelio, to the hearing today. Robert lives in Charlotte, and he and his wife, Christi, are the proud parents of three beautiful children: Nicholas, 18; Christopher, 15; and Lindsey, 10. He volunteers his time with the Boy Scouts of America and is a leader in the autism community in Charlotte, as two of his three children are affected by autism.

Bob, I want to personally thank you and Christi for traveling to Washington to testify today about the challenges your family has faced and will continue to face as a family affected by autism. I know the hopes and fears we have for our children can be profound and intensely personal. So I admire your courage and the courage of all of our witnesses today in coming here to speak about your deepest hopes and fears publicly.

It will help Congress better understand your unique challenges, and I truly believe that public policy in this area will be better because of your testimony, and my vision today is that it will help us to get those final 24 Senators signed on.

I thank all of our witnesses. I thank you, Mr. Chairman. I yield the floor.

Senator CASEY. Senator Burr, thank you very much for your testimony and for your great work on this.

These days, having folks work together across party lines and across the geography of this Capitol is all too rare, and I am grateful to have such great support in both places, and I am grateful to be working with Senator Burr.

I will introduce our witnesses in the order that they are to appear, but I know that Congresswoman Cathy McMorris Rodgers will be here a little bit late, but I will give you kind of a brief biographical sketch of her, and, if she arrives, then we can have her testify first. Otherwise, I will turn to Sara Wolff and go in that order.

Representative Cathy McMorris Rodgers is the chair of the House Republican Conference, making her the fourth highest Republican and the highest-ranking female Republican in the United States House of Representatives.

Cathy grew up on a family farm, worked at a small business, and was later elected to the Washington State House of Representatives in 1994, where she later served as the House Minority Leader in that chamber.

She was elected to the U.S. House of Representatives in 2004. And she and her husband have three children, the oldest of whom, Cole, was born in April of 2007 with Down syndrome. Congresswoman McMorris Rodgers is a leading disabilities advocate and the founder and co-chair of the Congressional Down Syndrome Caucus.

So we will be welcoming her shortly. Of course, she has a much longer biography that I could read, but we are going to try to get to all of our introductions as we have them set forth.

Next is Sara C. Wolff, someone I know well and, as I mentioned before, a fellow Lackawanna County resident. Sara is a self-advocate and motivational speaker. She works, as I referred to earlier, two jobs, one at the Keystone Community Resources Office of Advocacy and the other job as a law clerk in a law firm that I know well, led by Attorney Todd O'Malley, someone I have known for years.

Sara serves on the board of directors of the National Down Syndrome Society, the Arc of Northeastern Pennsylvania in Scranton, and the State board of Arc in Harrisburg, in our State capital.

Sara is a leading advocate for the ABLE Act. That is what is called an understatement. And she recently authored a *Change.org* petition that got over a quarter of a million signatures. Not many of us can say that.

After Sara, as Senator Burr noted, is his fellow North Carolinian, Robert D'Amelio from Charlotte, NC. He is serving as the director of data center operations for Fidelity Information Services, the largest financial services company in the United States.

Bob is a father of three children and has been an advocate for people with autism for over 10 years, serving as the advocacy chair of Autism Speaks in North Carolina, co-chair for the Autism Speaks North Carolina Walk, and a board member of the Autism Speaks-Carolinas Chapter.

Bob, we are grateful you are with us today to share your own story and grateful for your advocacy.

Lastly, we have Chase Alston Phillips, a financial advisor from Arlington, VA, who has worked for Merrill Lynch since 2008. Mr. Phillips specializes in the development and implementation of financial strategies for individuals and families living with disabilities and special needs, including multigenerational wealth management and family-related trusts.

In addition to his work as a financial advisor, Mr. Phillips volunteers with Quality Trust for Individuals with Disabilities, a nonprofit disability advocacy organization.

Chase, we are grateful you are here with us today.

So, we want to thank you for being with us, all of our witnesses and the audience. Your full testimony will be entered into the record. We appreciate you observing and adhering to the time limit of 5 minutes. That will allow us to have ample time for questions.

So, Sara, why don't we start with you?

STATEMENT OF SARA C. WOLFF, SELF-ADVOCATE AND BOARD MEMBER, NATIONAL DOWN SYNDROME SOCIETY, MOSCOW, PA

Ms. WOLFF. Good morning. My name is Sara Wolff. I am 31 years old, from Moscow, PA, and I happen to have Down Syndrome. I am honored to be here today on behalf of the National

Down Syndrome Society to testify before the subcommittee. I am excited to share my story today and discuss how the Achieving a Better Life Experience Act, best known as the ABLE Act, will dramatically change my life forever.

This is not my first time to DC. I have traveled here countless times to advocate for the ABLE Act. Last year, I lost my mother and number-one fan, Connie, to a sudden, rapid illness. She was my strongest supporter and accompanied me all over this great country for speaking engagements and conferences. Together we have increased awareness and advocacy for people with Down Syndrome and other disabilities by sharing our stories. We traveled all over together to inspire others to make a difference.

While I know my mother continues to watch over me from above, it is our memorable moments and life lessons that she taught me that inspire me to continue to do all that I can to pass the ABLE Act this year. You will hear me say this a lot in my desperate tone today—this year. My mom and I had many conversations about the ABLE Act. She said, “Sara, we have to get this bill passed.” She promised me she would be at the signing of this bill. I want to keep this promise alive for her, for me, and for the thousands of people with Down Syndrome and other disabilities.

With my whole life ahead of me, I need an ABLE account to plan for my future now, and I am not alone. People with Down Syndrome and other conditions are outliving their parents. My dad, Dennis, sister, Jennifer, and brother, Randy, are here with me today. My family, like so many others, needs to rest assured that they can easily care for their children and adults with disabilities.

This is the fair and right thing to do. Just because I have Down Syndrome, that should not hold me back from achieving my full potential in life. I can work a full-time job, be a productive member of society, and pay taxes. But because of these outdated laws, people like me are held back in life.

Currently, I cannot have more than $2,000 in assets before my government aid is cut off. These days, $2,000 is not a lot of money, and the rising costs of housing, transportation, and medical assistance make it tough for me to save.

Working two part-time jobs, my employers know I cannot earn more than $700 a month to maintain my government benefits. The ABLE Act would provide a way for Americans with disabilities to save for their futures and hold meaningful jobs. This year, I authored a *Change.org* petition calling for Congress to pass the ABLE Act. To date, it has over 260,000 signatures and counting.

People beyond the disability community think that the ABLE Act is a good idea and a no-brainer. Even the *New York Times*, in a recent editorial, urged Congress to move the ABLE Act.

We now have 74 cosponsors in the Senate, including Leaders Harry Reid and Mitch McConnell, and 366 cosponsors in the House on the ABLE Act. This is a historic number and shows the need and urgency to pass ABLE. That is 83 percent of the entire U.S. Congress. I am only 31 years old, but I cannot remember a time when that many members of Congress agreed that much.

I want to reiterate that with the ABLE Act, we are not asking Congress to create a new program or give us a handout. We are asking for an opportunity to use savings tools that other Americans have access to today. Passing this landmark legislation will help people with disabilities realize and achieve their hopes, dreams, and aspirations.

I want to thank our champions of this bill for their leadership, dedication, and making the ABLE Act a reality for me and others with disabilities.

In closing, I want to thank Ranking Member Enzi for helping to call today's hearing and for his cosponsorship. I want to thank Senator Burr from North Carolina, our ABLE champion, for his commitment and leadership to the ABLE Act. I also want to thank Congresswoman McMorris Rodgers, a fellow panelist here today, and her colleagues, Congressmen Ander Crenshaw, Pete Sessions, and Chris Van Hollen.

A big special thanks to my hometown Senator Casey and dear friend for calling today's hearing and all he has done for me and all people with disabilities. You made the ABLE Act happen, and I am so excited and look forward to joining both Senator Casey and Senator Burr with President Obama at the White House when he signs this bill into law this year.

Thank you.

Senator CASEY. Sara, thank you very much. We are grateful for that statement.

[The prepared statement of Ms. Wolff appears in the appendix.]

Senator CASEY. We are joined by Congresswoman Cathy McMorris Rodgers.

Sara, just as you were starting, she walked in the door. So that is good timing.

Representative MCMORRIS RODGERS. I got to hear it all. Excellent. Excellent.

Senator CASEY. But we are grateful that the Congresswoman is here, with such a busy schedule as both a Representative and also in leadership. Most of us around here only have one set of responsibilities. She has two major responsibilities while she is here and, of course, as a wife and mother.

So we are grateful you are with us, and you get at least as much time as Sara did.

STATEMENT OF HON. CATHY McMORRIS RODGERS, MEMBER, U.S. HOUSE OF REPRESENTATIVES, SPOKANE, WA

Representative MCMORRIS RODGERS. Well, just a big, big thank you, Senator Casey, for the invitation to be here, for your leadership, for holding this hearing. And thank you to Ranking Member Enzi and all the Senators and my fellow panelists, a packed-out room. Millions of people all across this country are grateful for you holding this hearing today, drawing the attention on the ABLE Act.

It certainly is very important legislation to ensure that those who have disabilities have the opportunity for a better life that can come to them through basically a 529 account that would be set aside. We call it ABLE—Achieving a Better Life Experience.

We have, as Sara mentioned, 74 Senators now who have cosponsored the legislation—tremendous bipartisan support—and 366 House sponsors. We rarely see this kind of overwhelming bipartisan support for an issue, and this is the year—I want to join in saying—this is the year we are going to get it on the President's desk.

But this legislation is not about Senators and Representatives achieving legislative success. It is about people like Sara, it is about people like my son Cole—who was also born with an extra 21st chromosome—people who need financial security and peace of mind, people who deserve an opportunity for greater independence that sometimes our current laws limit.

Right now, individuals with disabilities and their families spend countless hours worrying about their financial security. How are we going to pay for medical care that is not covered by the health care plan? How do we make it work to get much-needed job skills, training, and still pay the bills at the end of the month? Questions like these generate unnecessary worry and concern, because, too often, individuals and families have to pick and choose what care and services they can afford.

Our outdated laws encourage men and women with disabilities to resign themselves to a life of dependency by spending down their assets rather than saving them for future expenses. Unless families have the resources to hire an attorney to create a special trust or some other complicated savings vehicle, there is no other option to establish financial security without risking access to critical government programs for individuals with disabilities. I just do not think that is right.

As Americans, we believe in empowering all people regardless of where you come from or who you are. Policies like the ABLE Act will bring this very important empowerment to millions of Americans, transforming them from a state of dependence into one of independence.

For me, the ABLE Act is much more than just a piece of legislation that will help so many. It is also personal. When my son Cole was born, my husband and I were presented with many of the similar joys and fears that all families experience, and I want nothing more for him than for him to be able to reach his full potential, live his life to the fullest, and I am concerned that I see Federal policies that potentially place limits on his opportunities.

The ABLE Act will change that. It will help make sure that Sara and Cole and millions like them who have special needs will be able to save for their futures and reach their full potential. With overwhelming support from the House, the Senate, and the American public, it is time now to get the ABLE Act across the finish line, and I am proud to stand with all of you to advance this critical legislation.

Thank you again for your time, your commitment, and your leadership on this important issue.

Senator CASEY. Congresswoman, thank you very much for your presence here today, your testimony, and your personal witness on this issue.

We know that you have a busy schedule, so you are welcome to stay as long as you want, and we will have testimony from two more witnesses and then questions. But we are grateful for your leadership on this for such a long time, and we are obviously grateful you are with us this morning.

[The prepared statement of Representative McMorris Rodgers appears in the appendix.]

Representative McMorris Rodgers. Thank you very much. Thanks for having me.

Senator Casey. Thank you.

Bob, do you want to go next? Thank you very much for being here.

STATEMENT OF ROBERT D'AMELIO, VOLUNTEER ADVOCATE, AUTISM SPEAKS, CHARLOTTE, NC

Mr. D'Amelio. Chairman Casey, Ranking Member Enzi, Senator Burr, and members of the subcommittee, thank you for the opportunity to speak to you on behalf of Autism Speaks, the world's largest science and advocacy organization, and for the ABLE Act. My name is Bob D'Amelio, and I am a father of three children: Nicholas, Christopher, and Lindsey. My wife Christi is here with me today.

My story is about a small, middle-class family in Charlotte, from the great State of North Carolina. I am a data center manager for FIS, and my wife, Christi, is a realtor. We have lived in North Carolina now for 17 years, and we have had some of our happiest and saddest moments in that State. Like many families across the country, our family is an autism family. Both of my sons are affected. Christopher is more severely affected than his brother Nicholas.

I have been advocating for better autism services since 2001. I am a volunteer vice-chair of the Autism Speaks chapter in Charlotte and have chaired the Walk Now for Autism Speaks in Charlotte six times. This year's walk will be held at the zMAX Dragway on Saturday, September 27th, and we expect 8,000 people to be present. That number of people should not be a surprise to anyone, that turnout. According to the Centers for Disease Control, in North Carolina, one in 58 children has autism, and one in 35 boys in North Carolina has autism spectrum disorder.

These numbers are higher than the national average. Children like Nicholas and Christopher live in Charlotte, elsewhere in North Carolina, and in towns and cities and States across the country. These children need access to proven behavioral therapies and good school programs. Many need medications to manage their disabling symptoms.

None of this comes cheap. According to the research funded by Autism Speaks, the lifetime cost of care for an individual with autism averages $2.4 million when the autism involves intellectual disabilities and $1.4 million when it does not.

Families who have children on the spectrum need to be able to save for their future. This is where the ABLE Act would help. The ABLE account would enable families like mine to save for housing, job support, education, and other services, without fear of losing Social Security or Medicaid benefits. The current 529 plans fall short for many individuals with autism and other disabilities who cannot choose to go to college.

As much as anything else, the ABLE Act is about fairness. If Christi and I can use a college savings account to provide for our daughter Lindsey's future, why can we not use something similar to take care of Nicholas and Christopher? I would love to sleep at night knowing that I am doing everything I could to secure the future for my children.

My son Christopher is a very smart young man, but he will need a job coach and, at some point, a residential program. Saddling my daughter Lindsey with a big financial burden is not fair when Christi and I can provide for Christopher. Lindsey is already mature beyond her 10 years. She knows she will be looking after Christopher and keeping tabs on her brother Nicholas for the rest of her life.

Autism teaches you to be strong, to persevere when others tell you to give up, to celebrate the small steps in life, and to appreciate what you have. Autism demands your time and energy and changes you as you live with the family.

Parents like Christi and I want to do everything we can for our kids, for all our kids, disabled or not. The ABLE Act would allow families to make the future more secure for children with disabilities, taking the burden off siblings, other family members, and the government.

Please take this simple step of passing the ABLE bill. We will all sleep better for it.

Thank you.

Senator CASEY. Thank you so much for your testimony, especially for bringing both your own witness as well as your own advocacy to this issue. We are grateful.

[The prepared statement of Mr. D'Amelio appears in the appendix.]

Senator CASEY. I have been using first names, so, Chase, I will just ask you to testify next. Sara, Bob, and Chase.

STATEMENT OF CHASE ALSTON PHILLIPS, FINANCIAL ADVISOR, ALEXANDRIA, VA

Mr. PHILLIPS. Good morning. It is a pleasure to be here today and to testify before the Senate Finance Subcommittee on Taxation and IRS Oversight. I am testifying today on behalf of the National Down Syndrome Society in this effort to pass the Achieving a Better Life Experience Act, better known as the ABLE Act.

This piece of legislation will afford millions of individuals with disabilities the opportunity to experience the American dream and to achieve the highest reaches of success that this country has to offer, opportunities that should be rightly available to all of its citizens.

My name is Chase Phillips, and I have lived with a neurological birth defect, Spina Bifida, for all 29 years of my life. As a disabled individual, I have been fortunate to partake in many of the same life events as my able-bodied peers.

My determination to thrive has led me to excel in many areas of my life despite my limitations. I was a coxswain on the United States National Rowing Team because I had the competitive hunger to represent my country and compete at the highest level that my sport had to offer.

I earned a bachelor of arts degree and graduated from the University of Wisconsin. Being able to go away to school enabled me to learn the life lessons that are unique to living on one's own while attending college.

I chose a profession in finance that is very competitive and extremely challenging because I wanted to build a successful business and help people along the way.

I married a wonderful woman because I wanted to experience the joy of connecting with a lifelong partner and starting a family.

I volunteer with many disability nonprofits around the area because I have the desire to connect with individuals who are not much different from me—all of this while living with a disability that has had its challenges.

My story is not unlike that of many other disabled Americans. However, stories of success are the exception, not the norm. There are many people living with disabilities who struggle to live independently, who desire to hold well-paying jobs so they can support themselves. Under the current system, these individuals will survive, but few are able to truly thrive.

I am in a unique position because my personal experience living with a disability has intersected with my professional expertise as a special needs financial advisor. I currently run a practice at Merrill Lynch that specializes in developing and implementing financial strategies focused on improving the financial well-being of individuals living with special needs.

In total, the four advisors within our practice have over 8 decades of combined experience dealing with persons with disabilities. Three of our team members have disabilities themselves or have a family member living with a disability. We are fighting on the front lines of this battle both personally and professionally.

On a daily basis, we see the challenges that families and individuals face as they strive to provide for themselves and their loved ones. Many of our clients are currently enrolled in Supplemental Security Income and Medicaid programs and thus must live within the program's $2,000 asset ceiling in order to remain program-eligible.

These are people who seek to learn independent living skills so that they can hold a job and contribute to society. But because of these asset restrictions, many individuals will never live on their own.

For example, with these program restrictions, many people would not be able to save enough money for the first and last month's rent on a new apartment. This rule also limits the abilities for individuals to save for the down payment required to purchase a home. As a financial advisor, we recommend that our clients keep 3 to 6 months' worth of expenses in cash reserves in preparation for life's unexpected turns. This kind of planning becomes impossible with a $2,000 asset ceiling.

Asset restrictions chain individuals to levels of poverty and provide no real incentive for them to hold higher-paying jobs. Currently, over 70 percent of adults living with disabilities are living at home with their parents or caretakers. Four in 10 individuals aged 21 to 64 with a disability are currently employed. That is a 41.1-percent employment rate as compared to 8 in 10 adults living without disabilities who are employed.

There are tools currently available to help those with disabilities preserve their benefits while keeping assets held in trust for their benefit. By using a properly drafted and administered special needs trust, the disabled individual will continue to qualify for means-tested programs such as SSI and Medicaid. However, the special needs trust may not distribute money to pay for basic items such as food and shelter or other goods and services that the Social Security Administration categorizes as support and maintenance.

As such, the beneficiary's SSI benefits may be reduced or eliminated if the trust pays for those basic needs. The theory is that, since SSI benefits are specifically intended to pay for a person's food and shelter, the more those goods and services can be funded by another source, the less SSI benefits are needed. To magnify this issue, disabled individuals are not permitted to save in other tax-advantaged saving vehicles such as 529 accounts and Roth IRAs because these assets are counted as part of the $2,000 asset ceiling as per SSI guidelines.

In essence, Warren Buffett can gift $14,000 per year into a 529 college savings account and receive the benefits of those assets growing free of taxes, assuming they are used for qualified education expenses. Yet, a disabled American receiving SSI is not afforded this right and thus is not only denied the right to utilize such a tax vehicle, but is essentially unable to save for their own retirement and education. If this is not considered discrimination, I do not know what is. It is not only unfair, it makes no sense.

The ABLE Act will allow individuals with disabilities to save money in a tax-sheltered savings account in order to pay for qualified expenses such as education, housing, transportation, employment support, and assistive technology. These assets would not be counted against the disabled individual for purposes of qualifying for SSI, Medicaid, and other means-tested programs. This account will serve as a self-sufficient booster for disabled individuals to live independently, go to college, get married, and start a family.

No longer would an individual have to decline a higher-paying salary for fear that their assets would eclipse the $2,000 limit. The ABLE account is not designed to replace SSI, Medicaid, or the special needs trust, but rather to supplement these current programs, thereby enabling individuals with disabilities to reasonably plan for the future.

The ABLE account will be more transactional and also easier to administer for day-to-day spending needs. This account serves as the perfect complement to a special needs trust because it fills the gap between the short-term funding needs covered by SSI and the longer-term investments held within a special needs trust.

This piece of legislation is 8 years in the making. Let us make it happen this year.

Thank you.

Senator CASEY. Thanks very much, Chase. Thanks for bringing your professional expertise to this as well.

[The prepared statement of Mr. Phillips appears in the appendix.]

Senator CASEY. I just have one question for Sara, because we are running close to the time we have a vote. I want to let my colleagues ask at least one question, if not more.

Sara, I wanted to ask you about this: you have two jobs you are working and this, I guess I would call it imperative, because of the way the rules work now, that you can only set aside a certain number of dollars, can you talk about that and how your life would change if ABLE passes and you do not have to have that kind of special arrangement about how much you can save at one time?

Ms. WOLFF. Well, I work 3 days a week at O'Malley and Langan and 1 day a week at Keystone, but I work with my employers to ensure that I do not earn more than $700 a month to avoid losing critical benefits.

Senator CASEY. That arrangement does not make a lot of sense when you could be doing a lot more than that. You could be setting aside a lot more money for your future, and that is one of the basic reasons why we want to pass the Act.

I think, for the record, it is important for me to say that your petition now has more than 250,000 signatures. You are at 260,000. I should have known that it would be higher than any number I pointed to.

Senator Enzi?

Senator ENZI. Thank you, Mr. Chairman. I will just ask one question as well and then submit some in writing for them to answer, because this is some great opportunity for us to get additional information.

I would ask a question of Mr. Phillips, because you obviously work with financial advising. One of the concerns that we hear from people who might qualify is that, if they do this ABLE account, they might not qualify for the Supplemental Security Income, the SSI, and for Medicaid.

Are there boundaries that parents should be aware of with these accounts? What would disqualify a disabled individual with these accounts? Are there any restrictions?

Mr. PHILLIPS. The ABLE account would not disqualify families from becoming eligible for SSI and Medicaid. It is intended to put money away so that those assets will not be held against them for purposes of qualifying for those benefits.

Regarding limitations that families should know about, a big one is, with the ABLE account, there is a $100,000 cap, but only for purposes of qualifying for Supplemental Security Income. So if the ABLE account eclipses the $100,000 mark, the Supplemental Security Income would be put in suspension until the account came below the $100,000 limit. That $100,000 cap would not influence Medicaid.

The other thing that parents should know about is that, upon the death of the beneficiary, any money left over in the ABLE account would be subject to a Medicaid payback provision, again, if there is money left over.

So those are two major caveats that families should be well-aware of, but I am hoping that this account will be a great first step for families, and this has just been a big part of why families do not plan and why they are overwhelmed.

This ABLE account can be set up relatively easily. That is what is so exciting to me as a financial advisor, that families can finally start to take action.

Senator ENZI. Thank you. Thank all of you for your testimony.

The question that I hope you will give some thought to, to provide some written answers to me is, how are we going to notify people that this has happened once it has happened?

So I will need some help on that. I will yield the balance of my time to Senator Burr, who has had a magnificent hand in doing this.

Senator CASEY. Thank you, Senator Enzi.

Senator Burr?

Senator BURR. Thank you, Mr. Chairman.

Chase, let me just say I think you must have become a financial planner at about age 10, looking at you. [Laughter.] You know it well, and thank you for the expertise you bring to the families that are touched by your advice.

Bob, let me just turn to you. What worries you and your wife the most about your boys' future?

Mr. D'AMELIO. There are lots of things that worry me. The biggest thing that keeps me up at night and thinking about it is planning for, especially, my son Christopher's future, him having to be a burden on my daughter Lindsey. Already at 10 years old, she is mature beyond her time. I mean, at 10 years old, here is this young girl saying she does not want children because she is afraid of autism.

So things like the ABLE Act can allow Christi and I to help lessen that burden later on, because, at some point, someone is going to have to look over him in the future, when Christi and I are no longer around, and it is probably going to be my daughter Lindsey.

In an ABLE account, we can put money away to help her ease that burden. That is what keeps me awake at night and thinking, where will he be when I am 60, 70, 80, 90, or gone, what will he be doing? My goal for him is to be a taxpayer in this economy and have money in an ABLE account to help with job support or job coaching or training. I mean, I know it sounds simple, but my goal is for him to be a taxpayer.

Senator BURR. I guess it would be appropriate to say women can handle a lot more than men can, and I am confident your daughter is going to be able to fill in wherever needed.

Let me just ask you: if ABLE did not happen, what are you doing to plan, and what is the typical family trying to do?

Mr. D'AMELIO. Today we are putting money away in a 529 account for Lindsey, talking to family members right now who may want to leave money for Christopher, telling them the rules and understanding that, and looking at the legal costs of sitting down with an attorney and forming a special needs trust to do that. But in a lot of families with autism, there is not a lot of disposable income out there to go and spend those attorney fees to get a special needs trust and all the care and feeding that trust will require.

So it is very difficult for families, especially in the autism spectrum, in order to have the vehicle to save in.

Senator BURR. If you do not mind, can I ask you to address a little more the financial challenges that your family and other families face?

Mr. D'AMELIO. With two boys on the spectrum, over the years we have racked up medical bills that I would hate to even count right now, Senator. We got to a point about 9 years ago, 8 years ago, where my family felt we had to declare personal bankruptcy. I mean, the hardship on families of the cost of autism is tremendous.

Therapies, like behavioral analysis—you are talking $60,000 a year for a 2-year-old child. We do not pay that for college at some colleges. So the costs are overwhelming, and there are many families, whether it is across North Carolina, Senator, or across this country, who are just drowning in it trying to take care of their children.

Senator BURR. I know we have a vote that is going to happen any minute. Let me just say, if I can, Mr. Chairman, this is the norm, it is not the exception, and, if I had any wish, it would be that there was not a limit, that families could take care of the future of their children and their grandchildren in a fashion that relieved any fear that, when they leave this earth, they are financially going to be taken care of.

Unfortunately, we all deal with the Congressional Budget Office, and it dictates, to some degree, what we are able to do, how we are able to do it, when we are able to do it, and—I can only say this as one member of the Senate—I hope in the near future we will look at how we transition that institution, as it has become, to change and to reflect reality a little more.

I have said that the most difficult thing for a member of Congress is to see the human face behind every issue that we deal with. Sometimes it is easier than others.

Let me commend all of you who are here and those who have fought this fight and are not here. What you have been able to do is, you have been able to show members of Congress the human face behind this issue. That is why there are 74 co-sponsors in the Senate, that is why there are 366 co-sponsors in the House, that is why this bill will pass overwhelmingly, because every member can associate with it a face, a family that is affected. And I think from what Bob and I have done we believe, Chase, this will have a positive impact on those lives, and I think that is why we are here.

Thank you very much for your testimony.

Thank you, Mr. Chairman.

Senator CASEY. Senator, thank you very much.

I reiterate or incorporate by reference what Senator Burr said about what all of you have taught us about what stands behind bills and policy like this. So we are grateful for the families and grateful for the advocates who have made our momentum possible.

I wanted to get a little bit into the detail of how this bill will help families, because we do have a vote, but we moved our questioning a little faster than I thought we would have, thank goodness. So we have a little extra time.

As many of you know, in terms of what is covered by the bill—I am just reading from a list here, not a complete list, but here is what the funds in an ABLE account would cover.

The following is not an exhaustive list, but allowable expenses include: education, housing, transportation, employment support, health prevention and wellness, and it goes on and on, because, when I say that this effort is an affirmation that people with a disability or people with disabilities, plural, have a lot of ability—they can go to work, they want to work, they want to maybe have an apartment or get on the bus or travel in some way to their work, they want to contribute and be part of the fabric of this country—there is no reason why we should be holding them back because we have not gotten around to making a slight change in the tax code.

So it really is that simple. But, Mr. Phillips, I wanted to ask you—this is technical, but it is helpful to have some additional guidance on this. Some people might say, well, this sounds like a good idea, but there are other vehicles out there, and I can find a good tax lawyer, a consultant, advisor, accountant, pick your expert, and they can design something very similar to this, and it does pretty much everything that ABLE accounts would do.

Can you walk us through why that does not work? That is not to say that there are not some options, but why does that not work for folks who may not have access to those experts, number one, necessarily, but why does it not work and what is the mechanical or structural reason why we need to have ABLE accounts?

I know it is by way of reiteration, but it is important.

Mr. PHILLIPS. Yes. So there are special needs trusts that are available—first-party special needs trusts, third-party special needs trusts, pool special needs trusts—and they are excellent vehicles, and they all have their place to supplement the ABLE account.

But what the ABLE account offers is tax efficiency, to be able to make a contribution into the 529 ABLE Act and to make some earnings on it and withdraw them tax-free to pay for the things, the everyday things, that individuals with disabilities need. That tax status does not currently exist within the special needs trust accounts that we have.

Secondly, there are a lot of misconceptions about trusts. I think that individuals think that maybe they are only for the wealthy, which could not be further from the truth, but it prevents some families from taking action. They are worried about the costs; they are worried about the complexities. They look at this planning and see the equivalent of trying to eat an elephant in one sitting.

Families are overwhelmed with what they have going on—PT, OT, IEP meetings, a day-to-day routine—and the longer-term planning piece takes a back seat because they see it as a very, very complex challenge.

What I think would happen with the ABLE account is, because these accounts can be set up relatively easily, you are going to see a lot more families take action and take action now so that their child, down the road, or their loved one, down the road, is not at risk of losing their government benefits. Perhaps their son or daughter is going to be able to work and live and really contribute to society and make their own money, and now they will have that account that they can save into without worrying about eclipsing SSI limits.

Senator CASEY. Well, I am grateful for that. I know we will have to wrap up.

Senator Enzi, do you have anything else to say?

Senator ENZI. I would just make a final comment, and that is that we are on the verge of passing the autism reauthorization bill too. So I would appreciate any support you could give on that. I think we can get it done very shortly, and that will help in some way, hopefully, to find a solution.

So I thank you for this hearing and particularly this testimony and the answers that we will get in the future.

Senator CASEY. Senator, thank you so much for your work.

I want to thank each of our witnesses.

The vote has started. We have a little bit of time, but we wanted to wrap up so that folks would not have to wait for an adjournment, and we can come back.

But it is a good time to adjourn. We know why we need to do this. Now we just have to complete the race. I am not going to get into football analogies, red zone, but it is something like that. We are getting close.

Just for the record, Senator Warner will submit a statement for the record. I want to make sure that that statement is incorporated into the record by consent.

[The prepared statement of Senator Warner appears in the appendix.]

Senator CASEY. Once again, in addition to thanking the witnesses, the families, the advocates who are here, I also want to let Senators on the committee know that they can submit statements and questions for the record to the Senate Finance Committee in the next, I guess, 5 days. That is the usual limit for these.

But we are grateful for the work that has been done. Let us go out and pass the ABLE Act.

Thanks, everyone. We are adjourned.

[Whereupon, at 11:09 a.m., the hearing was concluded.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

OPENING STATEMENT OF SENATOR ROBERT P. CASEY, JR.

"Saving for an Uncertain Future: How the ABLE Act Can Help People With Disabilities and Their Families"

July 23, 2013

This morning we convene the Finance Committee Subcommittee on Taxation and IRS Oversight to discuss an important topic—how we can help individuals with disabilities and their families save for an uncertain future.

I would like to thank Chairman Wyden and Ranking Member Hatch for the opportunity to hold this hearing and our Subcommittee Ranking Member, Senator Enzi, for joining me today. I would also like to thank Senator Burr from North Carolina, who has been tireless in his efforts to create a more sound future for those living with disabilities through the ABLE Act.

Right now, the tax code provides incentives for Americans to save for important priorities, such as retirement or college, through tax-advantaged savings accounts. However, those with disabilities are not afforded the same opportunity to save for their future.

In fact, many adults with disabilities cannot save money to cover costs related to their disability without becoming ineligible for programs like Social Security Disability Insurance or Medicaid that provide a necessary lifeline to so many in need.

This dynamic forces individuals with disabilities to rely on their family or community, but this support is often not enough to cover their long-term needs.

Take the experience of Sara Wolff, a fellow Pennsylvanian who is here to testify today. Sara has two jobs but has to carefully plan to ensure she never amasses more than two-thousand in assets or lose critical benefits.

This situation is unacceptable, and Congress can and should help resolve it. Individuals with disabilities should be able to save for their future costs on an even playing field with other citizens.

The ABLE Act would fix this unfair dynamic by creating tax-free savings accounts for individuals with disabilities. Specifically, it would build on the popular Section 529 college savings account program to allow families who have a loved one with a disability to similarly save tax-free for qualified disability expenses. Beneficiaries will be able to make tax-free withdrawals from their ABLE accounts to cover basic needs like education, housing, transportation and healthcare. Benefits provided through private insurance, the Medicaid program, the beneficiary's employer, and other sources would be supplemented, but not supplanted by the legislation.

The ABLE Act is an affirmation that people with disabilities have the ability to live a life full of opportunity and achievement. Today's hearing will address the need for ABLE accounts from the perspective of individuals living with disabilities, advocates, lawmakers and financial planners. Through the testimony of our witnesses, we will highlight the challenges individuals and families face planning for the future, the benefits and drawbacks of the current savings tools available, and how ABLE accounts can provide an additional tool for those in need.

It is my hope that the record we build today will pave the way to passage of the ABLE Act, which enjoys wide bipartisan support in both the Senate and House of Representatives with 75 cosponsors in the Senate and 366 in the House of Representatives.

No other bill in Congress has this level of bipartisan, bicameral support. This level of support is a testament to the hard work of families and other disability advocates, many of whom are present here today. It is also reflects the importance of what the ABLE Act does.

We want all 535 Members of Congress behind this important legislation, and we need to build on our momentum in order to get the bill passed when we return from the August recess.

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AUTISM SPEAKS
It's time to listen.

TESTIMONY PRESENTED TO THE SENATE FINANCE COMMITTEE SUBCOMMITTEE ON TAXATION AND IRS OVERSIGHT

BY ROBERT D'AMELIO, VOLUNTEER ADVOCATE FOR AUTISM SPEAKS

Chairman Casey, Ranking Member Enzi, Senator Burr, and members of the subcommittee, thank you for the opportunity to speak today on behalf of Autism Speaks, the world's leading autism science and advocacy organization, for the ABLE Act. My name is Bob D'Amelio, and I am the father of three wonderful kids, Nicholas, Christopher, and Lindsey. My wife, Christi, is here with me today.

My story is about a middle class family from the city of Charlotte in the great state of North Carolina. I am a data center manager for FIS and Christi is a realtor. We have lived in North Carolina for 17 years and some of our biggest and saddest moments have happened there. Like many families across the nation, our family is an autism family – both of my sons are affected, Christopher more severely than his brother.

I have been advocating for better autism services since 2001. I am the volunteer vice-chair of the Autism Speaks chapter board in Charlotte, and have chaired Walk Now for Autism Speaks Greater Charlotte six times. This year's walk will be held at the zMAX Dragway on Saturday, September 27th. We expect seven to eight thousand people to walk on behalf of those affected by autism.

That's a large number of people, but no one should be surprised by our turnout. According to the Centers for Disease Control and Prevention, in North Carolina 1 in 58 children – 1 in 35 boys – have an autism spectrum disorder. These numbers are higher than the national averages. Children like Nicholas and Christopher live in Charlotte, elsewhere in North Carolina, and in towns, cities, and states across the country. These children need access to proven behavioral therapies and good school programs. Many need medicines to manage their most disabling symptoms.

None of this care will come cheap. According to research funded by Autism Speaks, the lifetime cost of care for an individual with autism averages $2.4 million when autism involves intellectual disability and $1.4 million when it does not. Families who have a child on the spectrum need to be able to save for the future.

This is where the ABLE Act would help. An ABLE account would enable families like mine to save for housing, job supports, education, and other services without the fear of losing Social Security or Medicaid benefits. The current section 529 plans fall short for the many individuals with autism and other disabilities who cannot or choose not to go on to college. As much as anything else, the ABLE Act is about fairness. If Christi and I can use a college savings account to provide for our daughter Lindsey's future, why can't we use something similar to take care of Nicholas and Christopher?

I would love to sleep at night knowing that I was doing everything I could to secure the future of my children. My son Christopher is a very smart young man, but he will need a job coach and at some point a residential program. Saddling my daughter Lindsey with a big financial burden is not fair when Christi and I can provide for Christopher. Lindsey is already mature beyond her ten years of age. She knows that she will be looking after Christopher and keeping tabs on Nicholas for her entire life.

Autism teaches you to be strong, to persevere when others tell you to give up, to celebrate the small steps in life, and to appreciate what you have. But autism demands your time and energy and changes how you live as a family. Parents like Christi and I want to do everything we can for our kids – for all of our kids, disabled or not. The ABLE Act would allow families to make the future more secure for children with disabilities, taking the burden off siblings, other family members, and government. Please take the simple step of passing ABLE. We all will sleep better when it becomes law.

Thanks again for letting me testify before you.

OPENING STATEMENT OF SENATOR MICHAEL B. ENZI

"Saving for an Uncertain Future: How the ABLE Act Can Help People With Disabilities and Their Families"

July 23, 2014

Mr. Chairman, thank you for holding this hearing on the Achieving a Better Life Experience Act (the ABLE Act). I appreciate having this opportunity to take a closer look at how this legislation can help individuals with disabilities and their families live a more fulfilling and rewarding life and chart a more certain future. I am looking forward to this open discussion about the merits of the bill.

Mr. Chairman, history has taught us that individuals with disabilities can flourish with the help of their families and a supportive community. Disabilities that were once thought to be disqualifying and limiting in terms of an individual's ability to express themselves are now seen as challenges that can be overcome. Today, those living with disabilities have shown they can contribute in meaningful ways to our culture, the arts, our business community and to society at large. The success and flourishing of individuals within our communities makes our society more inclusive and gives everyone an opportunity to thrive and pursue whatever path they choose to follow to their ultimate happiness and fulfillment.

One of the bold statements made by our Founding Fathers as they worked together to create our nation was their recognition of our inherent rights to "life, liberty and the pursuit of happiness." Few countries can boast of having been created with an eye toward that kind of freedom of expression. The legislation we are discussing today takes another step forward in the effort to make the promise of the Declaration of Independence ring true for us all.

Mr. Chairman, if we walked over to the Capitol Visitor Center, we would see several poignant illustrations of this. One of the most well-known and best loved examples of what is possible for those living with disabilities to achieve is seen in the life of Helen Keller.

Helen Keller, the famed author and political activist of the early 20th century, became deaf, blind and mute as a result of an early childhood disease. Those challenges did not stop her from eventually graduating from college with a Bachelor of Arts degree, however. Some might have thought her hopes would never be realized and her goals would be impossible for her to achieve. Where she saw opportunity, many others saw a dream that would never come true. She knew better and she used that determination to create her own path of what was possible for her to achieve.

Helen Keller was a pioneer who lived her life by leading the best way – by example – and that is why she will always be remembered for her accomplishments. She became the first significantly disabled individual to graduate from college. She went on to write and publish her own autobiography and 11 other books. She served as a prominent spokeswoman for social causes of her day, including women's suffrage and the needs of the physically handicapped. She lived a life that was so inspirational and noteworthy that she has been immortalized on stage and screen.

One hundred years later, we still marvel at her achievements. She remains a remarkable and inspiring woman who taught us what one person can do who refuses to give up on a dream, no matter the obstacles put before her. Although she accomplished tremendous things, she was blessed that she didn't have to go it alone. She had a supportive family who loved her and a mentor who refused to let her quit. It made a difference for her to have the support, encouragement, guidance and direction of her lifelong instructor and companion Anne Sullivan. Added to that, was the active involvement of her parents, and the financial support of others. Together with her unique spirit and commitment to making a difference in the world she was able to follow her dreams and reach her destiny.

You will find her story in our nation's Capitol. Her statue, part of the Capitol Statuary Hall collection, now graces the Capitol Visitor Center. It's featured in a spot in the Capitol seen by countless visitors each day. Even now, it would be difficult to find the bearer of a message that is more relevant to our hearing today than Helen Keller, a message that serves to constantly remind us that individuals with disabilities, given the right help, can grow and flourish – and become more productive than anyone else would have ever imagined.

The ABLE Act would take a small step in helping disabled individuals support themselves, pursue their dreams, and put themselves in a place of greater financial security. It would allow them and their families to open tax-exempt accounts so that they can plan how to best use their own funds to cover their living expenses. In our economy, many families are very familiar with the challenge of saving for the future well-being and needs of their children. A family with a disabled individual faces even more unique emotional and financial obstacles. The ABLE Act would help these families meet these challenges, whether it's paying for specialized care or a more individualized education to maintain their health and their independence, or provide for a better quality of life.

I've long been a supporter of enabling families and communities to meet the needs of the disabled. A few years ago, I introduced legislation to expand and revitalize the two main federal employment and training programs for persons with significant disabilities, paving the way to create more, better jobs and restore accountability to prevent waste, fraud and abuse.

In my own state of Wyoming, Alees Rogers in Uinta County Wyoming has been helped by her community. She has a developmental disability and, with assistance for housing and other care, she was able to take a job after graduating from high school at First Bank where she sorts mail and shreds documents. She also lives independently in her own apartment. The ABLE Act could help her to accomplish even more as she continues to plan for her future.

Wyoming has also developed an innovative college program called the Wyoming Institute for Disabilities (WIND), to help individuals with developmental disabilities, their families, professionals, and University of Wyoming students through education, training, community services and early intervention. These types of services combined with the ABLE Act strengthen the opportunities for individuals with intellectual disabilities to grow, achieve, and succeed.

I don't think there was ever a more well-known or better dreamer than Walt Disney. He knew a thing or two about how to make the impossible a reality. He once said, "If you can dream it you can live it."

Let's help more of our disabled individuals and their families to do exactly that. Let us work together with them to take their dreams from the drawing board to reality by offering them the support they need to make it happen.

While it is true that the initial discovery of an obstacle or a limitation can often be dispiriting, or discouraging, when our families and communities circle around those facing such challenges, we can help them to rise above them and succeed beyond anything they could have ever imagined. The ABLE Act will help to make that happen by providing more financial stability so that we can all chase after our dreams and fulfill our Founding Fathers' promise of the pursuit of our happiness. That is why this legislation has found overwhelming support from 75 members of the Senate and 366 members of the House.

I welcome our witnesses today. I appreciate their taking the time to join us for this important discussion and I look forward to their testimony.

Thank you Mr. Chairman.

TESTIMONY OF CONGRESSWOMAN CATHY McMORRIS RODGERS

"Saving for an Uncertain Future: How the ABLE Act Can Help People With Disabilities and Their Families"

July 23, 2013

Good Morning Mr. Chairman, Ranking Member Enzi, and other members of the Committee. I am honored to be here this morning with Sara Wolff and our distinguished panel on behalf of the millions of Americans with disabilities and their families who would have the opportunity for better lives with the 529 accounts that would be created under the Achieving a Better Life Experience Act (ABLE).

I would like to thank you, Mr. Chairman, for your commitment to this issue, as well as Senator Burr; the 74 Senate cosponsors; Representative Crenshaw, the bill's lead House sponsor; and the 365 House cosponsors. Rarely, do we see such overwhelming bipartisan support for an issue, which has the potential to land on the President's desk.

But this legislation is not about Senators and Representatives achieving legislative success. It's about people like Sara and my son Cole, who was born with an extra 21st chromosome. People who need financial security and peace of mind. People who deserve the opportunity for greater independence that is limited by our current laws.

Right now, individuals with disabilities and their families spend countless hours worrying about their financial security. How will we pay for medical care not covered by our health care plan? How can we make it work to get much-needed job skills training and still pay the bills at the end of the month? Questions like these generate unnecessary worry and concern because – too often – individuals and families have to pick and choose what care and services they can afford.

Our outdated laws encourage women and men with disabilities to resign themselves to a life of dependence by spending down their assets rather than saving them for future expenses. Unless families have the resources to hire an attorney to create a special trust or some other complicated savings vehicle, there is no other option to establish financial security without risking access to critical government programs for individuals with disabilities. And that's just not fair.

As Americans, we believe in empowering all people regardless of where you come from or who you are. Policies, like the ABLE Act, will bring this very empowerment to millions of Americans – transforming them from a state of dependence into one of independence.

For me, the ABLE Act is much more than a piece of reform legislation that will help so many – it's personal. When my son Cole was born, my husband Brian and I were presented with the same joys and fears that all families experience. We want Cole to live his life to the fullest and have every opportunity to reach his full potential. But, I see firsthand how our federal policies limit his opportunities because of his disability.

The ABLE Act will help change that. It will help make sure Sara, Cole and the millions like them who have special needs will be able to save for their futures and reach their full potential.

With overwhelming support from the House, the Senate, and the American public, the time is now to get the ABLE Act across the finish line. I'm proud to stand with all of you to advance this critical legislation.

Thank you again for your time and commitment to this issue.

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Chase A. Phillips

Financial Advisor and Advocate

Written Testimony before the Senate Finance Committee

July 23rd, 2014

Good morning, it is a pleasure to be here today and to testify before the Senate Finance Committee on Taxation and IRS Oversight. I am testifying today on behalf of the National Down Syndrome Society in this effort to pass the Achieving a Better Life Experience Act, better known as the "ABLE Act". This piece of legislation will afford millions of individuals with disabilities the opportunity to experience the "American Dream" and to achieve the highest reaches of success that this country has to offer, opportunities that should rightly be available to ALL of its citizens.

My name is Chase Phillips, and I have lived with the neurological birth defect, Spina Bifida, for all 29 years of my life. As a disabled individual I have been fortunate to partake in many of the same life events as my "able bodied" peers. My determination to thrive has led me to excel in many areas of life, despite my physical limitations. I was a coxswain on the United States National Rowing team because I had a competitive hunger to represent my country and compete at the highest level that my sport had to offer. I earned a Bachelor of Arts degree and graduated from the University of Wisconsin. Being able to go away to school enabled me to learn the life lessons that are unique to living on one's own while attending college. I chose a profession in finance that is very competitive and extremely challenging because I want to build a successful business and help people along the way. I married a wonderful woman because I wanted to experience the joy of connecting with a lifelong partner and starting a family. I volunteer with Children's National Medical Center because I have a desire to connect with kids who aren't much different from me. All of this, while living with a disability that has its daily challenges. My story is not unlike that of many other disabled Americans. However, stories of success are the exception, not the norm. There are many people living with disabilities who struggle to live independently, who desire to hold well paying jobs so that they can support themselves. Under the current system these individuals will survive, but few are able to thrive.

I am in a unique position because my personal experience living with a disability has intersected with my professional expertise as a special needs financial advisor. I currently run a practice at Bank of America Merrill Lynch that specializes in developing and implementing financial strategies focused on improving the financial well being of individuals living with special needs, regardless of their age or disability. In total, the four financial advisors within our practice have over eight decades of combined experience dealing with persons with disabilities. Three of our team members have disabilities themselves or have a family member living with a disability. We are fighting on the front lines of this battle both personally and professionally.

On a daily basis we see the challenges that families and individuals face as they strive to provide for themselves and their loved ones. Many of our clients are currently enrolled in Supplemental Security and Medicaid programs and thus must live within the programs' $2,000 asset ceiling limit in order to remain program-eligible. These are people who seek to learn independent living skills so that they can hold a job and contribute to society. But because of these asset restrictions many individuals will never live on their own. For example, within these program restrictions, many people would not be able to save enough money for a first and last month's rent on a new apartment. This rule also limits the abilities of individuals to save for the down payment required to purchase a home. As a financial advisor, we recommend that our clients keep three to six months worth of expenses in cash reserves in preparation for life's unexpected turns. This kind of planning becomes impossible with a $2,000 asset ceiling. Asset restrictions chain individuals to levels of poverty and provide no real incentive to hold a higher paying job. Currently, over 70% of adults with disabilities are still living at home with their parents or caretakers. Four in ten individuals aged 21 to 64 with a disability were employed (41.1 percent), as compared to eight in ten adults without disabilities.[1]

There are currently tools available to help those with disabilities preserve their benefits while keeping assets held in trust for their benefit. By using a properly drafted and administered Special Needs Trust, the disabled individual will continue to qualify for means tested programs such as SSI and Medicaid. The special needs trust may not distribute money to pay for basic items such as food or shelter or other goods and services that the Social Security Administration categorizes as "support and maintenance." As such, the beneficiary's SSI benefits may be reduced or eliminated if the trust pays for these basic needs. The theory is that since SSI benefits are specifically intended to pay for a person's food and shelter, if those goods and services can be funded by another source, the less SSI benefits are needed.

To magnify this issue, disabled individuals are not permitted to save in other tax advantaged savings vehicles such as Roth IRAs, 529 accounts, and 401ks because these assets are counted as part of the $2,000 asset ceiling as per SSI guidelines. In essence, Warren Buffett can gift $14,000 per year into a 529 college savings account and receive the benefits of those assets growing free of taxes (assuming they are used for qualified education expenses). Yet, a disabled American receiving SSI is not afforded this right, and thus is not only denied the right to utilize such a tax vehicle, but is essentially unable to save for their own retirement. If this is not considered discrimination then I don't know what is. It is not only unfair, it makes no sense.

The ABLE Act will allow individuals with disabilities to save money in a tax-sheltered savings account in order to pay for qualified expenses such as education, housing, transportation, employment support, and assistive technology. These assets would not be counted against the disabled individual for purposes of qualifying for SSI, Medicaid and other means tested programs. This account will serve as a self-sufficient booster for disabled individuals to live independently, go to college, get married, and start a family. No longer would an individual have to decline a higher paying salary for fear that their assets would eclipse the $2,000 asset limit. The ABLE account is not designed to replace SSI, Medicaid, or the Special Needs Trust, but rather to supplement these current programs, thereby enabling individuals with disabilities to reasonably plan for the future. The ABLE account will be more transactional and also easier to administer for day to day spending needs. This account serves as the perfect complement to a special needs trust because it fills the gap between the short term funding needs covered by SSI and the longer term investments held within a special needs trust.

This piece of legislation is eight years in the making. Let's make it happen this year.

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[1] Matthew W. Brault, *Americans with Disabilities: 2010: Household Economic Studies* (US Department of Commerce, Economics and Statistics Administration, US Census Bureau, July 2012).

STATEMENT OF SENATOR MARK R. WARNER

UNITED STATES SENATE
COMMITTEE ON FINANCE
SUBCOMMITTEE ON TAXATION AND IRS OVERSIGHT

Robert P. Casey, Jr., Chairman
"Saving for an Uncertain Future: How the ABLE Act Can
Help People With Disabilities and Their Families"
July 23, 2014

I am very pleased that the Finance Subcommittee on Taxation and IRS Oversight is examining the potential impact of S. 313, the Achieving a Better Life Experience (ABLE) Act on Americans with disabilities and their families. I am a proud co-sponsor of this bipartisan, bicameral legislation which would allow the one-in-five Americans with a disability to access tools to lay the groundwork for a brighter future.

Under today's laws, Americans with disabilities do not have access to savings tools similar to those afforded to other Americans choosing to save for college, health expenses, or retirement. They are thus discouraged from working and saving for critical long-term expenses. The ABLE Act's creation of 529A accounts for Americans with disabilities would enable them to contribute to America's economy while saving for expenses including education, healthcare, housing, employment and personal support.

By creating this important mechanism for saving, we ensure fairness for all Americans regardless of disability status. I am hopeful that the Finance Committee will move swiftly to approve the ABLE Act, and refer it to the Senate for further consideration.

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Sara C. Wolff
Self-Advocate & Board Member, National Down Syndrome Society (NDSS)

Written Testimony before the Senate Finance Committee
July 23rd, 2014

Good morning, my name is Sara Wolff. I am 31 years old from Moscow, Pennsylvania and I happen to have Down syndrome. I live a busy life – I have two jobs. I am a law clerk at O'Malley and Langan Law Offices in Scranton, Pennsylvania and work at Keystone Community Resources in the office of advocacy. I also serve on a number of state and local boards throughout Pennsylvania; I enjoy swimming, keeping up on social media, and my advocacy work. I have been a board member of the National Down Syndrome Society (NDSS) since 2007.

I am honored to be here today to testify before the Senate Finance Subcommittee on Taxation and IRS Oversight. I am excited to share with the Committee today my personal story and discuss how the Achieving a Better Life Experience Act, best known as the "ABLE Act", will dramatically change my life forever.

I especially want to thank my hometown Senator, Chairman Bob Casey, for being a Champion of the ABLE Act and calling today's hearing. I also want to thank Ranking Member Enzi for his leadership in calling today's hearing along with his cosponsorship of the ABLE Act. I also want to thank Senator Richard Burr from North Carolina, our other ABLE Act Champion in the Senate, for his leadership and dedication to getting the ABLE Act across the finish line this year. We couldn't do it without each and every one of you!

I want to share with the Committee my personal story and what brings me here today before this esteemed committee. This is not my first time to DC, I have traveled here countless times to advocate on the ABLE Act.

Last year, I lost my mother and number one fan, Connie, to a sudden, rapid illness. My mother was always my strongest supporter and always stood in my corner. She accompanied me all over this great country for speaking engagements, conferences, and appearances – and together, we helped increase awareness and advocacy for people with Down syndrome and other disabilities by sharing our stories. We traveled to Connecticut, Missouri, California, Oklahoma and many more states to inspire others to make a difference in the lives of all people with special needs. While I know my mom continues to watch over me from above as I continue to travel the country focused on my advocacy work, it's our memorable moments and the life lessons that she taught me, that inspire me to continue on my journey and to do all that I can to pass the ABLE Act (this year, you will hear me say this a lot in my desperate tone today – **"this year!"**).

My mom was my advocate. And, she and I had many conversations about the ABLE Act over the last several years. She said to me, "Sara, we have to get this bill passed." She promised me that she would be at the signing of this bill . I want to keep this promise alive for her, for me, and for the thousands of people with Down syndrome and other disabilities.

With my whole life ahead of me, I need an ABLE account to plan for my future **NOW**. And I am not alone. Like most individuals with disabilities, people with Down syndrome and other conditions are out living their parents. Families, like mine, need to rest assured that they can equally care for their children and adults with disabilities, just like they can for their other children and family members.

Just because I have Down syndrome, that shouldn't hold me back from achieving my full potential in life. I can work a full-time job, be a productive member of society, and pay taxes – but because of these outdated laws placed on individuals with disabilities, people like me are held back in life. This is the year, we call on leaders in Congress to put an end to the inequities that exist for people with disabilities by passing the ABLE Act and allowing individuals and families to save for the future and break down the barriers to employment for these individuals.

Currently, I cannot have more than two-thousand dollars in assets before the government aid that I need is cut off. In this day and age, two-thousand dollars is not a lot of money and with the rising costs of housing, transportation and medical assistance that I need, it is tough for me to be able to save. I currently work two part-time jobs, and my employers have been gracious enough to work with me so I do not earn more than seven-hundred dollars a month; and maintain my government benefits. The ABLE Act would provide a way for Americans with disabilities to save for their futures as we would be able to make a positive impact on the workforce and hold meaningful jobs.

The ABLE Act would amend Section 529 of the Internal Revenue Service Code of 1986 to create tax-free savings accounts for individuals with disabilities. The bill aims to ease financial strains faced by individuals with disabilities by making tax-free savings accounts available to cover qualified expenses such as education, housing, and transportation. The bill would supplement, but not supplant, benefits provided through private insurances, the Medicaid program, the supplemental security income program, the beneficiary's employment, and other sources.

An ABLE account could fund a variety of essential expenses for individuals, including medical and dental care, education, community based supports, employment training, assistive technology, housing, and transportation. The ABLE Act provides individuals with disabilities the same types of flexible savings tools that all other Americans have through college savings accounts, health savings accounts, and individual retirement accounts. The legislation also contains Medicaid fraud protection against abuse and a Medicaid pay-back provision when the beneficiary passes away. It will eliminate barriers to work and saving by preventing dollars saved through ABLE accounts from counting against an individual's eligibility for any federal benefits program.

Earlier this year, I authored a change.org petition calling for Congress to pass the ABLE Act. To date, my petition has over two-hundred and fifty thousand signatures and counting. This petition has been supported by people all over the country and even people beyond the disability community think the ABLE Act is a good idea and a no-brainer! Even *The New York Times* in a recent editorial urged Congress to move the ABLE Act!

We now have 75 cosponsors in the Senate, including Leaders Harry Reid and Mitch McConnell, **and 365 cosponsors in the House on the ABLE Act** – As you all know, this is a historic number and further shows the need and urgency to pass the ABLE Act. Last time I did the math, that's eighty-five percent of the entire US Congress supporting the ABLE Act. I'm only 31 years old, but I can't remember a time when in the last 31 years – that many members of Congress agreed on anything that much!

I want to especially thank our Champions of this bill for getting us to this point and making the ABLE Act a reality for me and all people with disabilities. Again, a special thanks to Senator Casey and Senator Burr; and Congresswoman Cathy McMorris Rogers, a fellow panelist here today, and her colleagues in the House - Congressman Ander Crenshaw, Congressman Pete Sessions, and Congressman Chris Van Hollen.

In closing, I want to reiterate that with the ABLE Act, we aren't asking Congress to create a new program or give us a hand out, we are asking Congress to give us the chance to provide and save through savings tools that all other Americans have access to today. I need a way to save for my future and the ABLE Act would do just that. Passing this landmark legislation will go a long way to help people with Down syndrome and other disabilities realize and achieve our own hopes, dreams, and aspirations. I want to again thank my dear friend Senator Casey for his dedication and leadership on behalf of all people with disabilities. I am excited and look forward to joining both of you - Senator Casey and Senator Burr - with President Obama at the White House when he signs this bill into law **this year**!

Communication

Developmental Pathways
Dedicated to Individuals with Disabilities

HEARING BEFORE THE

UNITED STATES SENATE

FINANCE COMMITTEE

ON

SAVING FOR AN UNCERTAIN FUTURE: HOW THE ABLE ACT CAN HELP PEOPLE WITH DISABILITIES AND THEIR FAMILIES

TESTIMONY OF

MELANIE WORLEY

CEO & EXECUTIVE DIRECTOR

DEVELOPMENTAL PATHWAYS

JULY 23, 2014

Developmental Pathways
Dedicated to Individuals with Disabilities

Thank you for inviting Developmental Pathways to provide a written statement on the issue of: Achieving a Better Life Experience Act of 2013 and, more specifically, establishing tax-exempt ABLE accounts to assist an individual with a disability in building an account to pay for qualified disability expenses. My name is Melanie Worley, and I am the CEO and Executive Director of Developmental Pathways.

Developmental Pathways is a Colorado based non-profit agency created to serve persons with developmental disabilities. It was established in 1964 as a community-based alternative to institutional care. Developmental Pathways has developed a broad array of services based on the principle that full inclusion and participation in community life is attainable for every individual with developmental disabilities.

Developmental Pathways provides services to developmentally disabled individuals and their families throughout each stage of life ranging from early intervention programs to adult supported living services. As a result of this commitment and experience we are able to speak on the needs and struggles of the developmentally disabled community. We are working with these individuals every day and have seen firsthand their barriers to success. We have seen through direct interaction with persons with developmental disabilities that one of these barriers to success is the opportunity to save funds and invest in their future. Developmental Pathways, through this testimony to the United States Senate, express our full support for the Achieving a Better Life Act of 2013 (S.313/ H.R. 647), referred herein as the ABLE Act, because we believe this legislation alleviates this barrier.

American families are currently given tools to save for the future, these tools take the form of tax advantages under Section 529 of the Internal Revenue Service Code that allows them to prepare and invest in their future through college savings accounts, health savings accounts, and individual retirement accounts. In the name of fairness, the ABLE Act broadens these tax advantages to include the developmentally disabled community by creating tax free savings accounts available to cover expenses such as education, housing, transportation, and health, referred herein as ABLE Accounts. The important element of this legislation is that it requires savings in ABLE Accounts to be disregarded in determining Medicaid eligibility. This provides individuals with developmental disabilities, and their families, a chance to be financially secure without losing the necessary aid needed to pay for the immense long-term medical bills that most individuals with developmental disabilities face.

These individuals are simply asking for equality of opportunity. The ABLE Act would give our clients, and the developmentally disabled community nation-wide, the opportunity to save for long term expenses that Medicaid and Supplemental Security Income (SSI) does not cover, for example, education, housing, and transportation. Under current law individuals with developmental disabilities can only save $2,000 dollars in assets and are not allowed to earn over $700 dollars a month. These figures are significantly below the national poverty line and block members of the developmentally disabled community from becoming self-sufficient. The ABLE Act would create real incentives for employment for an individual with a developmental disability because they would be able to earn a livable wage and save for housing and transportation, which provides independence.

More specifically, the ABLE Act will benefit the developmentally disabled community by allowing individuals and families to plan and save for higher education. Parents of children with developmental disabilities face unique challenges that require long-term planning to ensure the well-being of their children. Without the passage of the ABLE Act many parents are not able to provide sufficient stepping stones for their children's future. Of course, not all parents are able to provide their children with college funds, these individuals, if they wish to pursue a higher education, have to work and save for college themselves. College tuition prices alone have reached astronomical levels, as a result, because of savings and earning limitations, an individual with a developmental disability has an enormous barrier to higher education. This barrier can hinder the future level of income and independence of an individual with a developmental disability. Under the ABLE Act they will be able to work for a living wage and place money into an ABLE Account towards their education.

At Developmental Pathways our core principle is to help individuals with developmental disabilities attain full inclusion and participation in community life. Chairman Wyden and Ranking Member Hatch, the bottom line is that the ABLE Act will allow us to properly fulfill this principle by giving members of the developmentally disabled community the independence to sufficiently support themselves and become active players in their communities. With your support you can remove current barriers to success and grant individuals within the developmentally disabled community a sense of true autonomy. For these reasons, we strongly urge you to pass the ABLE Act and broaden equal opportunities for individuals with developmental disabilities and their families.

Another barrier to success that we, at Developmental Pathways, have seen is the Medicaid Redetermination process. We would like to propose a way to improve and expand the benefits of the ABLE Act by urging the committee to consider alleviating unnecessary stress and hardship for those in the developmentally disabled community by increasing the Medicaid Redetermination period from once annually to once every five to seven years. The current law requires each individual with a developmental disability who is receiving Medicaid to submit all necessary documentation every year. Once all of the paperwork has been sent in they will find out if they have been determined eligible for continued assistance. The reality for most people with developmental disabilities is that their disability status is not going to change in one year's time. This fact deems the process of having to re-apply each year costly, unnecessary, and inconvenient.

Almost always, individuals with developmental disabilities need a caregiver to fill out and compile all of the required paperwork and doctor visits for the Medicaid Redetermination process. This can be overwhelming, stressful, and place an unnecessary strain on the already demanding schedule of caregivers. More specifically, if the caregiver does not complete the process correctly the individual with the developmental disability will have their health insurance cancelled. The loss of Medicaid is catastrophic for someone who is developmentally disabled because of the many essential medications and escalating prices for health services. Persons with developmental disabilities must put this enormous part of their lives in the hands of someone else, trusting that they will complete it properly. As a result, some individuals with developmental disabilities must live year to year not knowing if their health insurance will be taken away from them.

The goal of the ABLE Act is to improve the quality of life for individuals with developmental disabilities by allowing them to plan for the future and become as self-sufficient as possible. By allowing individuals with developmental disabilities to re-apply for Medicaid every five to seven years you are allowing them to plan for the future, improve quality of life, and lessen one of the many burdens already facing the developmentally disabled community.

We believe the ABLE Act will have a greater and more effective impact by including the proposed changes to the Medicaid Redetermination process. This change would allow individuals with developmental disabilities to truly become more independent and create dreams for themselves, as American citizens do, without fear of looming medical expenses due to lifelong disability.

We thank you again for the opportunity to provide this written statement for the record and look forward to working with the Committee to ensure both healthcare benefits and successful futures for our nation's developmentally disabled citizens.