Speaker 1:

Welcome to the ABLE to Save Podcast series brought to you by the ABLE National Resource Center, which is managed by National Disability Institute. Hear from leaders in the public and private sectors, as well as from ABLE account holders and their family members about how ABLE accounts can be an effective savings tool to help improve health, independence, and quality of life for people with disabilities. And now here's your host and Director of the ABLE National Resource Center, Miranda Kennedy.

Miranda Kennedy:

Hello. My name is Miranda Kennedy and I'm the Director of the ABLE National Resource Center. Thank you for joining us today for the next in our ABLE to Save Podcast series. Before we get started, I would like to thank this week's ABLE to Save sponsors, ABLEnow and ABLEAmerica.

Miranda Kennedy:

Our theme this week is best practices and action steps for ABLE family members, and our podcast today is perspectives on ABLE for people with intellectual and developmental disabilities from a family member and ABLE subject matter expert.

Miranda Kennedy:

I'm really pleased to have my colleague, ABLE subject matter expert and good friend, Marlene Ulisky joining us today for our ABLE to Save Podcast. Marlene will be sharing insights and the perspectives she's gained from both her personal and professional experience working with people with disabilities and specifically people with intellectual and developmental disabilities over a number of decades. Marlene has worn many hats and devoted her entire career to helping people with disabilities achieve a better life experience. Her deep subject matter expertise and the innovative work she's done on the ABLE National Resource Center team has really elevated our work with individuals, families, service providers, and disability leaders and decision-makers in the ABLE space.

Miranda Kennedy:

On a personal note, I'm deeply grateful to have had Marlene and the rest of our dedicated teams by my side building the ABLE National Resource Center. I'm really pleased our audience today, all of you listening in and thank you for joining us, have this chance to meet and hear from Marlene in this podcast format to benefit from her unique perspective.

Miranda Kennedy:

So Marlene, with that, I'd like to invite you to tell our audience in your own words a little bit about your professional background and your connection to people with disabilities.

Marlene Ulisky:

Okay. Thank you Miranda. Thank you for that very, very nice introduction, and thank you for the opportunity today.

Marlene Ulisky:

I've worked in the disability area for over four decades already. I retired from the Social Security Administration after a 35 plus year career. I worked in a variety of roles at the Social Security Administration, from directing the largest disability hearing office in the country, to evaluating disability and writing judges' decisions, to serving as a work incentive or employment support expert for Social Security as one of only 56 people across the nation with that expertise. After I retired from Social Security, I knew I was going to continue working, and I was going to continue for a variety of reasons. I like the challenge, but there's an underlying reason too.

Marlene Ulisky:

After I retired, I worked for the Florida Office of Vocational Rehabilitation to help them to establish the Partnership Plus Program under the Ticket to Work legislation. And then I bumped back to Social Security just for a short time where they temporarily rehired some of us retired folks to transfer our knowledge to some of the younger staff. And then in about 2016, I was hired by the National Disability Institute, and that's what really changed my life. I've worked at the National Disability Institute on a variety of projects across the country, across the nation, and most recently for the past couple of years, I've worked for the ABLE National Resource Center.

Marlene Ulisky:

In addition to my work in the disability area, I wear another hat and that hat is so important to me. It's a hat that's the driving force beyond me continuing to work. It's the driving force in my quest to shape policy across the nation and to have an impact upon individuals with disabilities. That hat I wear is the hat of Aunt Marlene. I'm a huge advocate for my nephew, who has a disability.

Miranda Kennedy:

I really think that is the heart and soul of your work, Marlene. I mean, you're such an expert on all of these different topics and you have such a variety of professional backgrounds and work experiences. But in talking about being Aunt Marlene, can you tell us more about that and your role as an aunt to Jeremy and that story and how that has really impacted your work in this space, because you do wear multiple hats, but the hat of Aunt Marlene is the driving force, really the passion behind your work and your dedication to this?

Marlene Ulisky:

It is. It is, Miranda. Our family has faced a couple of challenges ... well, more than a couple of challenges, but two major challenges over the years. One of them was the birth of a child with a disability. That's my nephew, Jeremy. It's a birth we were unprepared for. The other was the passing of Jeremy's mother about 10 years ago. Let me start with Jeremy first.

Marlene Ulisky:

He was born a couple of years after I started working at Social Security, and his birth actually shaped my career and it continues to shape it to this day. I'll never forget the day he was born. I was in Oil City, Pennsylvania. I was traveling for my job with one of our judges. I remember receiving a call from my brother, and instead of my brother being happy and elated over the birth of his son, he was sitting in a stairwell. He was in a stairwell at Children's Hospital in Pittsburgh. He was almost crying because the doctor had just told him and told my sister-in-law that their child should be institutionalized because he was born with a developmental disability. You have to remember, this was back in the 80s and things like that were probably more common at that time. I knew what was going to happen. I knew that he wasn't going to be institutionalized.

Marlene Ulisky:

Jeremy came home. He came home to his loving family. He had an older brother and he was followed by a younger brother later on. He was a very happy child. He was socialized a lot. He participated in a lot of activities. He graduated from high school with a special diploma. Like many of the listeners today, he tried supported living and he became employed, but it wasn't a good fit for him at that time. He was a little too immature at that time and he moved back home. Although he didn't work, he did attend a day program for a bit of time, but he mostly socialized a lot. He enjoyed a lot of activities.

Marlene Ulisky:

And then a little over 10 years ago my sister-in-law, his mother, passed away and it was unexpected. It was at the young age of 52. Like many families, we didn't plan for that. We were busy. Everything was going smoothly and we didn't think about things like that. That was the day that changed Jeremy's world, and it changed our world. I think our family was a little more fortunate because I work in the disability field, and my work background, so I put on my work hat and I really got to work. I started looking for benefits and supports for Jeremy.

Marlene Ulisky:

We asked him what he wanted because our family believes in self-determination. We wanted to do what makes him happy. He was a very trusting young man. He still is a very trusting young man and he wasn't safe home alone, so we needed those supports and services. It took a village. You've probably heard that term before, "It takes a village," and it really did because we had to start building a circle of support around Jeremy to provide him what he needed. I didn't have all the expertise and I didn't have all the answers. I had many of them, but not all of them. It all started with a support coordinator. I'll never forget. His name was Todd. He was brilliant, very dedicated. We got Jeremy into a day program, a sheltered workshop, and then we got him onto a Medicaid Waiver. That's what started the whole process and started us thinking about Jeremy's future.

Miranda Kennedy:

Can you tell us a little bit more about Jeremy himself? You shared a lot, but tell us more about his life now and what your concerns and your family's concerns has been in the past, present and future related to his financial future, which is really a cornerstone and why people are joining to listen in because all of this ties into that piece. Can you speak to your family's experience related to Jeremy and his financial future?

Marlene Ulisky:

Yes Miranda. Like many individuals, he receives a disability-based benefit from the Social Security Administration. Some of those benefits are means tested. That means that the Social Security Administration looks at income and they look at savings or resources when they determine whether or not someone's eligible. I talked a little bit about Medicaid Waiver programs, and the Medicaid Waiver programs are means tested. They look at someone's income and their savings also. So we had to consider that.

Marlene Ulisky:

When Jeremy was in the shelter workshop ... I wasn't real thrilled with the fact of him being in a "day program sheltered workshop," but the program he attended was great. They taught him the skills he needed. He learned a lot of soft skills, and he actually learned skills that an employer needed. After a while, he kind of got bored there and he wanted a real job. That scared us a little bit. We wanted to push him forward financially, to help him to get him to do what he wanted to do, but it was scary because we knew about those limits, the income limits, the savings limits. So we had to take a look at that.

Marlene Ulisky:

We learned too about the ABLE accounts, the Achieving a Better Life Experience account. It's a nationwide law that was passed in December of 2014. It allows individuals who have a disability, they could be receiving a benefit or not receiving a benefit, it allows them to establish savings accounts or savings and investment accounts, which will largely not effect means tested federally funded government benefits. So we established the ABLE account for him.

Marlene Ulisky:

Like many families, we wanted him to be happy, we wanted him to be healthy, and we also wanted him to live in whatever setting he chose. Eventually he chose to move out. He wanted to move from his father's home and get "a place of his own" like many of us. We wanted to plan for when we were no longer in the picture. We wanted to have some supports in place, some services in place and protect his financial future so that could do the things that he loves. He loves things like bowling and basketball and gaming and Special Olympics and swimming. He just bought an electric guitar. He loves eating out. He loves food. We wanted to be certain that down the road, when we're no longer in the picture, he could still continue to do those things, or be able to fund the things he enjoyed.

Marlene Ulisky:

We also wanted to go a step further and we wanted it to be certain that we protected any health related needs that may arise. Maybe in the future he may need dental work. He wears eyeglasses sometimes. Maybe he would decide he wants laser eye surgery, and that's largely not covered by insurance. Maybe even he wanted things related to wellness. It could be he wanted to have acupuncture or a fitness membership. He loves working out. In fact, he does belong to his local Y and enjoys that very much. So in protecting his future, we opened up that account and that has opened up the world for him. He saves some of his earning in his account, and his father and I contribute to his ABLE accounts. We save money, and that's not counted against any benefits he received. As a family, we all continue to contribute to his wellbeing and to his future.

Marlene Ulisky:

In the past, with a lot of government benefits, you couldn't have more than $2,000 in a savings account, or it would mean that you were ineligible for services or support. That ineligibility for services and support, it's vital. It was vital for Jeremy. He really needed those services and supports so that he could enjoy his life to the fullest, and we didn't want to jeopardize that With his ABLE account, he can save for his future, we can save for his future, and it doesn't affect his means tested benefits.

Miranda Kennedy:

I think that's so important. You've talked here and shared it with folks, some measures that you've taken and your family has taken to help protect Jeremy's financial future, which is a key to all of this. Can you talk, too, a bit about have you and your family taken steps to increase Jeremy's understanding of ABLE accounts and financial products? Can you speak to that?

Marlene Ulisky:

We have. First and foremost, the top measure that we did take was we opened that ABLE account for him, and we opened it along with him, but as a family, we all continue to accumulate knowledge on benefits. As we were talking about earlier, you indicated that I was an expert and I have a lot of knowledge on benefits, but all of us, it's a learning process. Not a day goes by that I don't learn something new about benefits, so we continue to accumulate knowledge. I'm a certified benefits counselor, and even though I am certified and I could provide Jeremy's father with information on benefits, we thought it was best for Jeremy to hear this information from an independent counselor, and then I could reinforce what was said. That's what we did. We took Jeremy to a benefits counselor. He got the information he needed about benefits. He understood that ABLE was a special exempt account. He and his dad have a good understanding I would say from our benefits conversations, our current conversations and the conversations that we've had over the years.

Marlene Ulisky:

There were a lot of myths surrounding benefits. Jeremy's father received some of the information through some of the groups he belonged to, or just sharing of information from neighbors or from friends. One of those primary myths was Jeremy couldn't save over $2,000 otherwise his benefits would be gone. After we eliminated that myth and we decided to open up his ABLE account, he learned that he could open up an account in any state across the country. He didn't have to open up the account in his home state of Pennsylvania. It could be any state, so long as he meets the residence requirement if they have one, and most states don't have a residence requirement. We looked at two accounts and we decided to establish his account in Pennsylvania, that's our home state, because many states have a homestay tax advantage or tax credits. That is one of the things that I as a benefits expert for the ABLE National Resource Center recommend to individuals; always just look at your home state first.

Marlene Ulisky:

Also too, I think a lot of folks think that they can walk into just a brick and mortar bank and open up an ABLE account, and you really can't do that. All the plans across the country operate through an online presence. You can open up an account, but it must be online. The state treasurers' offices operate those websites or those plans. I just would urge people just to be a little cautious when conducting business on the web, just like they would be cautious when making any purchases on the web. If there are questions, contact that state program, the state plan. They have options where you could contact them either via telephone or you could write in and you can email them, but contact them if you do have questions.

Marlene Ulisky:

Jeremy doesn't have a guardian and he doesn't need a legal guardian. Jeremy appointed his dad and myself as agents with power of attorney to help him to manage that account. So his father and I, along with Jeremy decide what money is saved and what money is invested in his ABLE account. We could either invest it or we can save it, or we can do both. All of the ABLE plans across the country have various roles for people who are agents who have power of attorney, and some are limited and some are not.

Marlene Ulisky:

In our role, we can invest the money for Jeremy. We feel that having diversification or having his money in different pots is best for him given his age and given his goals. So we have his money in savings and we have it in a conservative option because we're concerned with losing money. But if someone was younger, if Jeremy were a younger person, we may want to invest that money perhaps in a more aggressive option. That money right now, it's really growing tremendously. I'm very happy and pleased with the growth. Jeremy hasn't taken any distributions or any withdrawals to date because all his needs are met. He works and he has money for his needs. His father gives him money as needed, and other needs are met through his supports and services that he receives.

Marlene Ulisky:

Before he opened his ABLE account though, there were some issues because his money was kept in a safe at the group home or the residential facility where he lives with another young man. There wasn't any interest paid on that money. There was little accountability, but every Friday they did count out the money as part of what they called "money management training". It was very limited. There wasn't a formalized curriculum. As I said, there was no interest paid on that money and it began accumulating. We had to worry about how much money is in the safe, because that could affect the means tested benefits that look at savings on money that he has liquid resources. That's when we actually did realize too, that he needed something more, something more than that group home provider could provide to him.

Marlene Ulisky:

That's when we made another big decision for his financial future. We decided that we wanted to secure a debit card for him. Now, most of the ABLE plans across the country have debit cards, and Jeremy does use a debit card. Right now it is not through his ABLE plan, but we plan to transition it over to that plan. It's really a good option. We have his paychecks directly deposited there so there's less cash being handled and there's more accountability.

Marlene Ulisky:

The card he uses right now, it's in his name. He can make purchases for whatever he needs. When he eats out, he uses his card. He has learned to tip with his debit card. He's slowly beginning to accumulate some of the skills that he needs. He has worked with someone, with staff at his home to purchase items on Amazon with their assistance. If he needs a little more cash, he will visit an ATM machine with staff. He knows how to use the ATM machine. He likes to use that ATM machine, and he can secure cash from that machine. He's made some big purchases already. He's purchased an electric guitar and amplifier. He also purchased a PlayStation with a lot of games, which are quite expensive.

Marlene Ulisky:

He knows how much money he has. His father showed him how to download an app to his cell phone. He showed him how to call in to secure his balance. Occasionally, we'll text him screenshots that show his balances so he's always aware of what his balance is.

Miranda Kennedy:

Marlene, in terms of thinking about this, this is all very strategic and also very caring. You're breaking things down for supporting Jeremy and his use of his ABLE account and sharing with our audience how he's really benefited from that and your whole family as well. One of the reasons I was really excited to have you on one of our podcasts is because those different hats you wear and how that's really benefited Jeremy and your family, and then keeping that in mind, how do we share with our audience some of the tips, some of the insights from your experience with Jeremy personally supporting him and your brother after the loss of Jeremy's mom, as well as the work that you're doing here at the center, sharing that with such a larger audience.

Miranda Kennedy:

Can you share advice you have from that perspective of Jeremy's aunt, but also the work you've done here at the ABLE National Resource Center, the questions that have come in, the presentations we've given and the materials we've developed, what advice do you have for family members who are listening in related to financial planning and products?

Marlene Ulisky:

Well, first of all, I think it's crucial, it's vital that the family and the individual with the disability increase their knowledge around benefits and work supports if that person is planning to work around financial products and around services and continue to build their knowledge base. They can continue to do that by attending our free webinars at the ABLE National Resource Center. We do have a large number of webinars on a variety of topics archived on the webinar, or you can actually attend a live webinars. If you do attend a live webinar, and you do have questions during that webinar, you can ask questions and they will be answered live in the chat box. Also by attending conferences to increase your knowledge around financial products or services. I would say join organizations which provide services to individuals with disabilities. To join parents groups. That's a great resource. And to share the resources you find with other individuals who may benefit from that. The ABLE National Resource Center has a variety of resources.

Marlene Ulisky:

We'd like to say that our website is content rich. It's content rich because not only do we have the webinars, but we also have other tools that you could use or other resources you can use. We have something new we just released last month. They're called decision guides. Right now we have five decision guides, which are pathways to answering questions on a variety of topics to lead you along the way. The decision guides contain information on whether or not someone is eligible for an ABLE program, or finding the funds to contribute to an ABLE plan, or identifying qualified disability expenses. Or what are qualified disability expenses? What can you use that ABLE account for? We have a fourth one; Understanding ABLE Account Savings and Public Benefits. That's very comprehensive. The last is ABLE Accounts for Working People with Disabilities. That goes into some of the Social Security work supports also. They're all really good resources.

Marlene Ulisky:

We encourage folks to actually continue to go back to the ABLE National Resource Center, revisit the website because we're always adding new resources. We have three new decision guides we'll be compiling by probably the end of this year on making smart financial decisions in investments. That's a biggie because some folks are really hesitant when it comes to investments. They don't know a lot about it. At the ABLE National Resource Center, we get a lot of questions on that. What we usually tell people are don't delay opening the ABLE account. If you're unsure about investing money in that ABLE account, then put it into the savings option. Opt to contribute all of your money to a savings account option until you gain more knowledge about investments.

Marlene Ulisky:

We do have a wonderful comparison chart on our website. We partnered with the Special Needs Alliance and we compiled this chart, which compares all of the options because folks can have an ABLE account and they could have a special needs trust or a pooled trust. They don't have to decide on one or the other because they can complement one another. We encourage you to visit our website and take a look at that tool. Take a look at the webinar we did on special needs trust also.

Marlene Ulisky:

There's toolkits. We have an Employer Toolkit. We have a Service Provider Toolkit. As I said, we have all of our webinars and archived webinars. I also would encourage you to start the planning process early. Know that sometimes something unforeseen happens. I had told you what happened with Jeremy's mom. That was something very unexpected and something we were not prepared for at that time. I think that I would recommend opening that ABLE account as early as possible and allowing it to grow. If your child does not receive a benefit from Social Security, perhaps your child is under the age of 18, and the only benefit they may be eligible for is SSI, and you don't qualify because of parental income, know that that doesn't mean that that child cannot have an ABLE account because you don't have to be receiving a benefit from Social Security to open an ABLE account. You have to have a disability, which began before the age of 26, and has markedly severe functional limitation.

Marlene Ulisky:

With that being said, we have another resource on the ABLE National Resource Center website and that's our Disability Certification Form. That was something we compiled earlier this year. We placed it on the website for those parents or providers, or even physicians who may need that. It points you to the resources or to the policy directive on ABLE accounts.

Marlene Ulisky:

I think also, too, if you are a Supplemental Security Income(SSI) or a Social Security Disability Insurance (SSDI) recipient receiving a benefit from Social Security, reach out to a benefits counselor. You can find free benefits counseling through choosework.ssa.gov. Those folks can help you to understand working, work supports, and ABLE accounts. Begin the dialogue early like we did. Talk about needs. Talk about wants. Talk about goals. Try to begin teaching your loved one or your child about money. Try to teach them money management skills at an early age. Finally, if you are a family member or a friend, become a member of someone's circle of support. Even though it could be challenging sometimes, I guarantee that it will be much more rewarding and fulfilling.

Miranda Kennedy:

Well Marlene, you certainly shared a lot of great insight and resources and strategies with our audience, our listeners here today. You are such an asset to us at the ABLE National Resource Center, and have had a hand in helping develop all of these materials and making sure that we're supporting people with disabilities, their families, as well as the service providers, the decision-makers, to financial advisers who access the resources we have and the different materials. Definitely encouraging folks to sign up for our newsletter and join us as we continue to develop. As you said, new decision guides. We're really here to try to break it down and make it manageable for folks to find what they need, if it's in one of our frequently asked questions, if it's in a Disability Certification Form, things like that.

Miranda Kennedy:

Thank you for joining us today. We'd like to thank again our sponsors for this week of ABLE to Save, ABLEnow and ABLEAmerica. I encourage you to check out the rest of our materials and information at the ABLE National Resource Center website, ablenrc.org. Thank you and have a good day.