

Jody: Welcome, welcome everyone. My name is Jody Ellis and I'm the director of the ABLE National Resource Center, which is owned and managed by the National Disability Institute, or NDI for short. And NDI is the first national organization that is committed exclusively to champion economic empowerment, financial education, asset development, and financial stability for all people with disabilities. This year we're celebrating our 20th year anniversary of working with partners across the country to build capacity, um, have uh, training sessions such as today, create systems change, test innovative approaches and lead research, um, in the financial empowerment arena. NDI has the pleasure of working closely with UT Health San Antonio's Department of Psychiatry and Behavioral Services to bring to you this seven part financial wellness series. We have collaborated with subject matter experts from various parts of the country, including Texas, and we want to bring you a variety of topics for you to build upon your knowledge to promote financial wellness and empowerment for yourself, for your loved ones, and for those who you support.

Two weeks ago, we recorded our first session on basic financial management skills to build a foundation for all the subsequent topics in the series. So today, second in the series, we present a session on supported decision making and it's often SDM for short. So if you do hear SDM, it stands for supported decision making. And today you are in for a treat to learn from one of the nation's most esteemed experts on supported decision making. Jonathan Martinez is the Senior Director for law and Policy for the Burton Blatt Institute at Syracuse University. In 2013, Jonathan represented Margaret Jenny Hatch in the Justice for Jenny case. And this was the first trial to hold that a person has the right to use supported decision making to make her own life choices instead of being subjected to permanent plenary guardianship. Uh, Jonathan has led SDM projects in New York, Nebraska, Ohio, California, Virginia, Vermont, Missouri, Kansas, and he has educated tens of thousands of people with disabilities, families and professionals from across the country. Jonathan has written or co-written over 60 publications and including the first textbook on supported decision making and the first theory to practice guidebook. So, Mr. Martinez, take it away.

Jonathan: Thank you so much, Jody. Hello everyone, everyone. My name's Jonathan Martinez. I'm honored to be here and I'm excited to talk to you about my favorite subject, uh, supported decision making. Supported decision making is, in my opinion, the greatest advance in human and civil rights for people with disabilities since the Americans with Disabilities Act.

Before we begin, before I put my slide deck up, I wanna talk to you about what we're gonna talk about today. Because our presentation's going to have two parts. The first part is what I'm going to call a why part, meaning why supported decision making is important, why you

should think about using it, especially in the context of whether or not to seek a guardianship. Um, you're gonna hear a lot and maybe you have heard a lot about supportive decision making being an alternative to guardianship, and it is, and we're gonna talk about that a little, but before we even get there, I want to say that even though SDM is in Texas and all over the country, recognized as an alternative to guardianship, I'm not here telling you that there should never be guardianships, that guardianship is wrong, that you're evil if you're a guardian, if you've recommended it. The point of the why presentation is to explain how supported decision-making could, if a person wants to use it and a person is able to use it, serve as that type of alternative and help improve their life outcomes.

Second part is gonna be a how part, how we can use supported decision making, especially in the financial arena to improve people's quality of life. So with that in mind, let's begin. Um, with that in mind, let's begin. Sorry for the technical difficulty. Um, I hit the wrong button and I'm so glad this is being recorded to hear that.

So as we begin, the very first thing I want you to think about is something that people don't often think about and that's their rights. Rights are things that we just kind of take for granted. We've been taught since we were in grade school that we have inalienable rights, that we have protected rights, that we have civil rights. What I want you to do right now is think about your favorite right? The one that if someone tried to take it away, you'd fight, you'd be offended. The right that makes you the proudest to be an American, proudest to be a human, the one that you would defend against any attempt to take it away. Is it freedom of speech? Is it freedom of religion? Is it freedom of elections? Is it the freedom to have life, liberty and the pursuit of happiness? Well, let me ask you, what do all of those rights have in common?

What they have in common is choice. Choice is what makes our rights real. Think about it. Freedom of speech is the right to choose what to say and what not to say. Freedom of elections, the right to choose the people who will govern us, freedom of religion, the right to choose where and how, and even whether we worship life, liberty, the pursuit of happiness, the right to choose, the type of life we live, where we live it, and who we spend our time with. So the right to make choices if you ask me, is my favorite, right? There's a quote up on your screen right now from a philosopher named Jean Paul Sarra who gets it right. He says, I am my choices. I cannot not choose even when we choose not to choose. That's a choice. We are the sum total of our choices. The good ones, the bad ones, the important ones, the silly ones. They all make us who we are. They have brought you here today. So to me, once again, the right to make choices is the most important one.

And clinically, the right to make choices is called self-determination. Maybe you've heard that phrase. It's all over the literature. I'm not a big buzzword person, but this is one that I

believe in, uh, to my core because self-determination is making choices. It's being in control of your life. People who are self-determined are the ones who do things in their lives instead of having things done to them. People who are self-determined make choices instead of having choices made for them, they are, as you can see on your screen, the causal agents, the actors in their life who do instead of being acted upon. And here's something that we know from about 40 years of research. And the beautiful thing about the things I'm telling you about is they're not aspirational, they're not hippie, trippy, vaporware. The things I'm telling you about are backed by years and sometimes decades of hard science. And here's something that we know, we know from study after study after study, that people with disabilities who have more self-determination, who make more choices, who have more control over their lives, have better lives. Study after study after study has shown that people with disabilities who make more choices are more likely to have better life outcomes, more likely to be higher educated, more likely to be employed, more likely to earn more money and take a lead role in managing their money.

But with that in mind, a second question. The rights, the ones that are important to you, the ones that you thought about when I asked you to do that, would they be worth anything if you weren't allowed to use them? If you had them but you couldn't use them? If I were to say to you, of course you have freedom of speech, it's in the Constitution, but you can only talk when I tell you, you can talk and you can only say what I tell you to say. That's not a right is it? What if I were to tell you that you have the right to vote, but you're only gonna vote for who I tell you to? That's not a right. So without choice, our rights really don't mean anything.

And that is what we've been doing to people with disabilities for about 1500 years. Um, about 1500 years ago in, in the western legal tradition, the, the very first time that in the Roman Empire, they brought all the laws of the country into one place and harmonized them. It was under an emperor named Justinian. It was called the Justinian Code. I am such a legal geek. I actually have a copy of the Justinian code and I've read it. I in fact named one of my sons, Justin, which tells you everything you need to know about me. But in the Justinian code, it was literally in the western legal tradition the first time all of a country's laws were in one place and could be enforced all the way through that country. So really in a very real sense, it was the first time that citizens of a country from one side or the other had definable identifiable rights. But one of the parts of the Justinian code says that if you are feeble-minded, and that was their word for people with disabilities, if you're feeble-minded, you had to have a curator put over you, someone to make decisions for you. And I've always thought that started kind of an expectation, or I call it a culture, an expectation that when people with disabilities have any limitations, they can't do anything and they need someone to do things for them. And that has followed us ever since.

In Great Britain where we got most of our laws from, they updated the Justinian code. What they said is that you are an idiot or a lunatic. And that was their word for people with disabilities, idiots and lunatics. You had to have a committee put over you to make decisions for you because you couldn't. In America, we've adopted that rule essentially and called it guardianship. Now like I said, there's nothing wrong with guardianship if that's what's needed. But studies show that guardianship is used very often and often far more broadly than it should.

And this is what I mean by that. Every state, your state included, has essentially the same guardianship law. It says, if a judge decides that I can't make some or all decisions in my life, I have to have someone make those decisions for me, the judge appoints someone to make the decisions and do the things that I truly can't. You have to ask, what can I do? What can't I do? And those things I can't do, someone else does. That person becomes my guardian. If it that were the way it worked, you'd have no bigger fan than me because some people need assistance in those types of ways. Some people can't make decisions in parts of their life and need someone to do that.

But here's what studies show us is that nine more than nine out of 10 guardianships take away all rights. Whether or not the person needs that, whether or not the person wants that. And that means guardianship is neither a good thing nor a bad thing. But it can be a dangerous thing. Imagine knowing that you could manage your own money. Imagine knowing that you had the ability to budget your money to decide what to save and spend on, but also knowing that you had difficulty keeping medical appointments and working with your doctor. You might not have a problem having someone help you or be the decider on medical care because you understand you might need that. But how would it feel to know that you had someone doing things for you instead of you, that you could do? And that's the problem.

Because when we overuse guardianship, when we do what I call over broad or undo guardianships, guardianships over people who don't need guardians or that take away more rights than people need to lose, that's when things can become difficult. Like the National Academy of Elder Lawyers said, guardians in that way can have complete authority over the lives of vulnerable people. Like the AARP said that type of guardianship gives someone else, a third party, sometimes a stranger, the right to make the most personal and intimate decisions in your life. Where you can go, what you can do, what type of healthcare you get and what you do with your money. What you can do with the money that you earn, the money that you have. Someone else can decide what it gets spent on.

And here's something else we know. Just like we know that when people have more control over their lives, when they have more self-determination, they have better lives. We know

the opposite is true. When people lose self-determination, particularly people with disabilities, lose self-determination in their lives, their lives get measurably worse. We've known for 50 years that the loss of self-determination, the loss of choice, can make people feel helpless, hopeless, and self-critical. The rest of that sentence is people won't behave 'cause they see no point in behaving. And that's not rocket science is it? If I say to you, you can't do this, you'll never going to be allowed to do this. How do you feel about yourself at that point? We also know that loss of self-determination leads to lower self-esteem, less uh, ability to function more passivity. And again, that's not rocket science. If I tell you again and again and again that you can't do something, are you feeling particularly motivated to try?

So once again, what that means is guardianship is neither a good or a bad thing, but it's an important thing that we have to make sure not to misuse. And that is the message that I'm giving in this first section of this presentation. And that's this the promise I made earlier. I'm keeping. Of course, there are times when guardianship is needed. If a person truly cannot make decisions, then a guardian is absolutely needed and helpful. If a person doesn't want to be involved in the decision making process and is putting his or her health or safety at risk, of course a guardianship can help. In an emergency and there's no one around to help, a temporary guardianship is a great stepping stone. It's a great temporary solution. So I'm not here to say, and you'll never hear me say there should never be guardianships.

But what I can tell you is that there should never be guardianships just because you have a certain diagnosis, you're a certain number of years old or because the two on the bottom that turned my stomach, that's the way it's always been and it's for your own good. I hear those time and time again in state after state, if I don't get guardianship over my son, my daughter, my brother, my mother, whomever, something bad might happen, they might make a mistake. So they might make a bad decision. They might waste their money, they might get swindled. And these are all the best of the motivations. It's for their own good that I see guardianship.

Well, one thing I do know is what the Supreme Court said almost a hundred years ago. There's a quote up on your screen and it's as true today as it was then. What the court said is that when we mean the most well, we have to be the most careful. When we take actions with the best of motives, but not understanding what they can lead to. When we take away people's rights for their own good, not understanding how that can be harmful based on study after study after study, then bad things can happen. The court said it very well, the greatest dangers to liberty lurk in the insidious encroachment by people of zeal, people who are well meaning but who don't understand the consequences of what they're doing.

I hear it all the time. Um, if I don't get guardianship, a person might waste their money. If I don't get guardianship, they might get taken advantage of. If I don't get guardianship, they might get hurt or make a mistake. And these are the best motivations. I never question a parent, a professional, a loved one who wants to help someone they care about. But I do always ask them to look in the mirror, because if what we're doing is prospectively taking away rights and taking away self-determination for people's own good, we need to look in the mirror. What I'll ask is, have you ever closed on a mortgage or signed a lease? Because when you do those, one of the things that happens is there's a pile of paper up to the sky and it gets handed to you either real or virtually online. Now one after a time and you're told, sign here, sign here, sign here. And I ask if you're like me, did you read that before you signed it? Because if you like me, you didn't, you just sign where they told you to. And what that means to me is that that's a horrible decision. I made a horrible decision. I put hundreds of thousands of dollars of my money, 30 years of my life in the hands of a bank without reading the fine print. Doesn't that mean I need a guardian over my money, 'cause I made a terrible decision?

What about, uh, consenting to surgery? I've had surgery uh, recently actually. And, and right before I had that surgery, I can tell you I had people in my face I'd never met before, saying words I'd never heard before. All of them shoving pieces of paper in my face saying, sign here. I'm your doctor. This is what I'm gonna do. Sign here. I'm your nurse. Sign here. I'm your anesthesiologist. Sign here. And I asked, did you read those before you signed them? Because if you're like me, you didn't. Which means that you put your life in the hands of strangers. You may have waived your right to sue in court. It's a terrible decision. Don't I need a guardian over my healthcare?

Have you, let me ask you, uh, five years after the pandemic started, and I think maybe we're finally, you know, getting used to being out and about again, but man, I had a game I played during the pandemic that made me feel good. And the game went like this. Maybe you've played it. Have a bunch of drinks. See what comes tomorrow from Amazon. I could tell what kind of day I had by what showed up on Prime tomorrow. Was I stress eating? Was it a piece of useless exercise equipment? Did I wanna be stress eating? Was it a piece of useless kitchen equipment? I made terrible, terrible financial decisions. And if you did, don't you need a guardian?

But here's the other side of that. I also ask people this and maybe you can answer these questions with me. Have you ever had a bad relationship that taught you what a good one is? Of course you have. Have you ever been a rescue buddy or been, uh, rescued by a buddy? Think about the phrases we use. Have you ever woken up in the morning and gone, wow, I'm never doing that again. But kind of glad it did. You know, we have phrases for that.

It's a teachable moment. It's a life lesson. It gives us something to talk about at parties. Those mistakes make us who we are. And you know what? Making those mistakes made you better, better, stronger, and smarter. So what I tell people all the time who say I have to do this to keep a person from making a mistake or getting hurt or anything like that, is I applaud your motivation. It's a good thing to want. But think about the consequences, because aren't we saying you're not allowed to grow like I did? You're not allowed to risk like I did. You're not allowed to learn like I did.

And you know, the science is scary. Like I told you, the vast majority of guardianships take away almost all of people's rights. And those overbroad or undue guardianships, remember some guardianships are absolutely appropriate. But the ones that aren't, the ones that take away more rights than a person need to lose or take away any rights than a person doesn't need to lose them can hurt people. There are studies showing that people who are in unnecessary guardianships can experience a significant negative impact on their physical and mental health. They feel less well, they do less well in some cases they live less long.

But on the other side of that are study after study after study showing that people with disabilities who have more self-determination, who make more choices, have a better quality of life, more financial independence, more community integration, more work, a better life.

And the number one reason I hear for guardianship is that I don't want my loved one to be hurt, to be abused, to be neglected. And, and there is no better motivation than that. There is no one on the side of the angels like a parent who doesn't want their child to be hurt. I am a parent, I know that. But what I do talk about when it comes to guardianship is science.

Up on your screen now is a, a summary of a study done by a professor named Rashida Keka in New York. She's a series of studies. This particular one looked at the interplay between self-determination, making choices and safety. Dr. Mko worked with women with intellectual and developmental disabilities. Um, if you don't know this, you showed women with disabilities are far more likely to be abused and neglected than anyone else in the population, physically, emotionally, sexually, emotion, financially. It's awful.

So what she did was she worked with that group and everyone in that group had similar abilities and limitations. I call it an apples to apples study. What she did was she did a classic study. She divided them up into two groups, an experimental group. And she gave this experimental group access to a curriculum, a recognized curriculum designed to enhance their self-determination, to teach them about making choices and why they should be making choices and having control in their lives. And she had a control group who she said, go live your life. After the curriculum was done, she brought them back

together and gave them a test, a recognized test, designed to measure people's ability to recognize potentially abusive situations and avoid them.

You know, what she found? And remember, apples to apples, the people with more self-determination, those who had had the curriculum, the ones who learned about it being important to make decisions, they were found to be better able to recognize potentially abusive situations and avoid them. And I say again, it's not rocket science. If you know it's your body, your life, your money, your stuff, aren't you more likely to fight like hell when someone tries to take it away?

So I've had cases and I've talked to judges across this country. I talked to parents, I talked to professionals, and I always say the same thing. Your, you have a good motivation. You want to protect people. But if you do want to keep people safe, don't start with taking their self-determination and rights away. Start with building up their abilities, building their awareness, giving them a choice, because people recognize and respect and want to protect their choices and they'll want to protect themselves.

And lastly, what I'm, what's on your screen now is my favorite study. I warned you I'm a geek. I do have a favorite study. It's called the National Core Indicator Study. It was done across the country, uh, on people with disabilities. It was done to look at their quality of life. And again, it was an apples to apple study. They said, um, the old names mild, moderate, and severe disabilities so that people with mild disabilities were compared to people with mild disabilities, moderate to moderate, severe to severe. And what the national court indicator study looked at was the impact of certain things on people's quality of life. One of the things they looked at was whether or not a person had a guardian. And in every state where this was done, that's almost all of them. They found the same thing. Apples to apples. Remember, people who do not have guardians were more likely to work, more likely to manage their money, more likely to live independently, more likely to have friends other than their staff or family, more likely to be part of their community, more likely to practice the religion of their choice. It was such a surprise that they did it again a few years later and found the same thing. And the most recent version of it, once again found the same thing. And it's not rocket science. Self-determination leads to a better quality of life.

So what we should be doing and where we can go from here is to say this, people should have self-determination to the maximum of their abilities. That's not a hard conclusion because we all want that in our lives. All of us want to be the person who calls the shots, who makes the decisions. So it is not a huge leap to say that we should do everything we can to maximize the self-determination of people with disabilities, including their right to have self-determination.

But that's not enough. We also have to understand that people with disabilities need help sometimes. I mean everybody needs help. Sometimes you should have seen me trying to get on this webinar. It took like three attempts and technical assistance and we had to do a practice. So we all need help in different ways at different times.

So here's my hypothesis. We need to find ways to maximize the self-determination of people with disabilities because that equals a better quality of life. 50 years of science say that. But we also need to make sure that people with disabilities have the help they need and that they want so that they can practice and use their self-determination safely and effectively.

And if you agree with that, I have a path forward for you. It's called supported decision making. I know it's 19 slides in, 20 minutes in, I'm finally getting to the point well supported decision making is a way to get to self-determination, a way to maximize control over your life. What is supported decision making? Good news. There's a definition on your screen right now. You can find this definition in articles, in textbooks. Um, you can read it for you, you can take a screenshot. Supported decision making is a recognized alternative to guardianship through which people with disabilities work with friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions about the need for a guardian. I had to read that really fast because it's a whole bunch of words. I know those words because I wrote them. Uh, this is my definition of supportive decision making that you'll see in the textbooks and the journals. And if you want, you can tell people that you were taught by the guy who wrote those words. But I wish you wouldn't, 'cause I hate these words. I hate this definition. I don't think this is supported decision making at all. Or at least it makes supported decision making sound like some kind of program or process.

So if you really want to know what supported decision making is, ask yourself this question. How do you make decisions? What do you do when you don't know what to do when you have to pay your taxes and you're like me and you're confused? What do you do? You talk to somebody, a professional, maybe, maybe you use TurboTax. What do you do when you don't know whether it's a good idea to buy something or to save money or invest in something? You talk to someone, a friend, a family member, a professional. What do you do when the doctor speaks jargon? If you're like me, you, you say, can you please explain that to me in really simple language. And uh, I've done that very recently. Please talk to me like I'm a 5-year-old so I can understand this. What do you do if you go to the auto mechanic and you don't understand anything about cars? I have a buddy I call and I ask questions. They want to do this, they wanna do that. Is it a good idea if you're doing that,

everything up to and including does this shirt go with these pants? You are engaging in supported decision making.

Because all supported decision making is, is getting help from people you trust and information sources that you trust, so you can understand the decisions you have to make and make them. And we do that every day. People with and without disabilities use supported decision making every day. We have cliches for it. We don't call it supported decision making, what we do. Because who calls it supported decision making? We just call it living life. I mean think about again the phrases that we have. Don't make a snap judgment. Don't make a rush to judgment. Don't go off half cut, get a second opinion. My dad always said if you measure twice, you only have to cut once. All of those things mean the same thing. Get the help you need to make the decisions you have to make. And when you do, you are using supported decision making.

The difference is when people without disabilities use supported decision making. When I say and believe me, I say this very often, when I say I don't understand, can you explain this to me? You know what people think. I am smart. People think I'm being wise. People think I'm getting a second opinion. People think I am making sure before I make a decision and we get complimented for that. But you know what happens when people with disabilities say, I don't get it, explain it. Time after time. And way too often society assumes they're dumb. Society assumes people with disabilities can't. Because going back to the just Indian Code Society has said, if you have limitations, it must mean you have an inability and that leads to the overuse of things like guardianship.

So I want you to think again about supported decision making because really the question of whether a person goes into a guardianship often comes down to a question of whether they are able. And we see that word in statutes all the time. Someone needs a guardian if they are unable to make decisions or they are incapacitated or they lack capacity. Well I want you to really think about what that means, what it really means to be able or unable. Because I think if you think about your life, you'll realize your ability is different than my ability. There are things that I can do right now that I don't need help doing. There are things that you don't need help doing. They're probably different from, there are things also that you might need some help to do. You might need some help. You have an idea, but you need a little bit of help, a little bit of advice, a second opinion. And there may be things that you simply cannot do unless you get that help.

So what does it mean to be able in those situations? Have you ever woken up not feeling well or stressed out and say, I better not deal with this issue today because it's not a good day for that. Were you unable on that day? What does it mean to be unable? If you want a great example of ability, when I go to the doctor, I tell the doctor what's wrong and I told you

I'm a big baby. I basically say, please give me something to make me feel better. The doctor will prescribe something, I will take what the doctor prescribed. I am able to make the decision to take that medication. But I don't know a damn thing about that medication. I'm not reading the fine print on the prescription bottle. I can't even spell azithromycin. I don't know the difference between that and erythromycin. But I have the ability to take care of my health because I have a doctor, who I trust, who is giving me advice and helping me make that decision. Otherwise, unless you are a doctor or have a medical license, you cannot take care of your health because you don't have the ability to diagnose yourself or prescribe for yourself. So that can't be the test of whether you are able, able has to include the help you might need. It has to consider the situation you are in.

So when you think about guardianship, I always ask people to answer two questions. If you are only able to make decisions and manage your lives when you have help, if you need help to make decisions and manage your lives, are you able? Because if the answer to that question is no, then we all need guardians because all of us need help to be able to do something in our lives at some point. So that's question one. If you need help, are you unable? And the answer to that better be no because otherwise all of us are unable.

The second question is this, before you seek or recommend guardianship, ask this question. What else have you tried? How can you know if someone is able or unable? The vast majority of the time, yes there are some people who are definitely unable. A person in a coma for example, is definitely unable to make decisions. But for the vast majority of times, the question really is what have you tried to help that person become able? What assistance have you provided? What have you tried or have you just assumed that a person has a disability and therefore is unable? Are we better? Aren't we, mustn't we be better than the Middle Ages in Britain where they described people with disabilities as idiots and lunatics and assumed they were unable? Haven't we come farther than that?

That's not just my position. That is the position of the National Guardianship Association. An organization made up of guardians by guardians and for guardians. And what they say is this, before guardianship, try something else. Try supported decision making. It might work, it might not. If it doesn't work, guardianship's fine. But what's the rush to it?

Because supported decision making can do for people with disabilities what it does for you and for me and for everyone else. Think about the way that you use supported decision making in your life. And yeah, I know you probably don't call it supported decision making, but think about the way you use support. Think about your friends and your family members who help you focus on the issue. See the forest for the trees who help you weigh your options. Make a pro and con list, help you narrow down your choices to make sure that the decision you make is the one that is the right one for you. That supported decision making.

And people with disabilities studies have shown can do the same thing. They might need more support, they might need different kinds of support, but the principle is the same.

In fact, this is the point in the presentation where people are always thinking, okay Jonathan, get to the point. Tell me what I do. Tell me where the book is. Tell me where the app is. Tell me what step one, step two, step three are. And that's when I can tell you the good news is, and you already know the answer to this, there is no one way to do this. There is no one size fits all method of supported decision making because you make decisions differently than me at different times using different help. For some people, all they need is what I call a shoulder to lean on an ear, to listen to informal support, someone to talk to some people.

And this is like me, have what I call go to people. There are people I go to for particular topics in my life. My sister is an educator. I go for her, go to her with questions about my son's schooling. My other sister, uh, specializes in working with older adults. We have been leaning on her as my mom has gotten older. I have a friend who knows about investing. I go to him with those questions. My other buddy, like I told you knows about cars. Go go-to people. And we can write those people into things like powers of attorney and supported decision making agreements.

Some people like to be even more formal and use things that were piloted in Texas called micro boards or circles of support. People who get together regularly live or now virtually to talk about my life with me, have discussions sometimes have debates so that the issues get a full airing and a full discussion like a personal board of directors so that I can make the decision that makes the most sense for me. Well all of those are supported decision making because all of them involve me going to you for assistance so that I can make the best possible decision. That's what supported decision making is.

It takes three things. It takes acknowledging that everyone has the right to make choices to the maximum of their ability. Everyone has that right to the maximum of their ability, whatever that ability is. And that's easy. That's the Declaration of Independence, right? We hold that truth to be self-evident that people have the right to life, liberty and the pursuit of happiness.

And the second thing is, I have the right to ask you for help. Doing something without you, assuming that means I can't do it and need someone to do it for me. And that's easy because we ask for help every day from people in our lives.

And last, we realized that there are as many ways to give and get help as there are people. First thing you try, may not work, never go to plan B before, man. Sometimes I go to plan Triple Q, something might work if you try to empower someone one way and it doesn't work,

try something else. Ask that person. How do you want to be helped? When do you want to be helped? And something may work, nothing may work. And if nothing works, guardianship is certainly an appropriate option. But we shouldn't rush into it. 1500 years since Justinian is enough time to say we should not assume people with disabilities can't do things.

And the reason I started talking about self-determination is this. We have studies that show that when people use supported decision making, they have more self-determination, they have more control over their lives. There are research and studies showing that. And if we know that supported self-determination is the key to a better life for people with disabilities and we can show that supported decision making leads to more self-determination, then why shouldn't we be trying this for people's lives?

There was a study I was a part of working with young adults with disabilities and we showed that those who used supported decision making were more independent. They were more confident. They said they were better at making decisions. People in their lives, their supporters said they made better decisions. And even in the middle of the pandemic we found out they were doing more things in the community, making more friends, having more activities. It's not rocket science, they were more self-determined and they had the opportunity to do that.

Now let's talk about financial planning and supported decision making because all those things I just told you about, all those methods of making decisions, all of that self-determination and supported decision making works in a number of contexts. I have worked with people on supported decision making in special education, employment in healthcare, and yes, financial planning because if it requires decisions, supported decision making can help a person do that.

Uh, first I want you to think about a service in your state called vocational rehabilitation. Vocational rehabilitation or VR is there to help people work. There's a link on your screen you can use to find your local vocational rehabilitation office. Wherever you are, there is one near that you can talk to. The whole point of VR is to help you get what you need to work. And VR can provide all kinds of supports and services. Things like counseling, things like education, things like job training and things like medical and mental health care.

But by I'm starting with vocation, rehabilitation is this. Far too many people with disabilities are afraid to work. They're afraid to earn money. And it's a good fear because time after time after time, what I hear is I can't work and I can't make and manage my money 'cause it might make me lose my benefits. And like I said, that's a true fear because if you are receiving public benefits, SSI, SSDI, Medicaid, supplemental food assistance, you are not

allowed to have much money. They say if you have more than \$2,000 in money and assets to your name with very few exceptions, you can lose your benefits. So people are afraid to work, they're afraid to have money.

Vocational rehabilitation can help you with that. If you work with your VR office on employment, they have a service called benefits planning. And benefits planning is designed to help you get the supports you need to manage your money so that you don't go over what we call the fiscal cliff to help you manage what money you make and how you spend it and how you report it. So if you work with your vocational rehabilitation office, and I strongly recommend that you do, if you are a person with disabilities or work with people with disabilities, I strongly recommend you apply for vocational rehabilitation if you haven't already. One of the things you should be asking for is benefits counseling to make sure you can keep your benefits, make sure that the money you make stays with you and does not cost you.

But there are other ways to use supported decision making specifically to manage your money. One of them is through a power of attorney. What you see on your screen, um, is the result of a person that I worked with, a mom who heard me speak and said, Jonathan, I buy in. I like this idea of supporting decision making but my son can't do it. My son has disabilities and he is gonna get ripped off. And the kid to his credit said, yeah, I, I think I'd get ripped off. So what we did, we worked together for a while to make a power of attorney. And a power of attorney really just says, I may have trouble doing something so I want you to do it for me or with me. And we wrote it in a very specific way. This family had a little bit of money. So we said, kid, you've got a budget of x. I mean imagine now with a prepaid debit card. This was before prepaid debit cards, but this is easy with a prepaid debit card. We said, you can spend up to this amount of money per week or per month when you go nuts, make decisions, make bad decisions, learn what it's like to have money and use it with the whole idea being he should take responsibility, have self-determination. But if you want to spend more than that, your mom has to sign off on it. So if you wanna buy a car, you can't sign a contract to buy a car, your mom would have to sign off on it. But here's where we did something differently. Instead of just saying Mom could say yes or no, we put the language in bold in the power of attorney that said before mom decides whether to say yes or no, they are going to have a conversation, they are going to talk about it and mom is going to give primary consideration to son's wishes, hear him out 'cause he may be right and he may be wrong. If he's wrong, it's a chance to have a conversation about money and learn. If he wants to buy a car, it's a chance to talk about having to earn money to make payments, having to not having to take care of the car, having to get insurance, having to work. And maybe that leads to getting supports and services like vocational rehabilitation. But the

supported decision making component, the conversation that leads up to the mother making the decision is the one that empowers the son to think about it and to do better.

And we did the same thing with bank accounts. Back in the day when you wrote checks, we said you could write checks up to a certain amount and set it on the check. More than X requires two signatures. So mom would have to sign off on spending above a certain level. And we used the same language before. Mom could say yes or no. They had to have a conversation to discuss the decision so that maybe he was right or maybe he could learn what it would be to be right going forward. And this is a way, if you think about it, to help people learn to do better. We included a clause that we'll talk about later called a growth clause with the idea that every year they would review how well he was managing his money. If he was doing it well, they would give him a larger allowance to use to spend money, to plan money. If he wasn't doing well, they would tighten it up, which is a great way to look at people who are getting older as well. We did that with my mom, frankly, we slowly limited the amount of money she could spend, but always kept her involved in the decision making so that she had the maximum self-determination she could. And here once again, when mom had to think about whether to say yes or no to a particular decision, they had to talk about it first. They had to discuss what to do first, to give him an opportunity both to influence the decision but also to get the support that he needed to make good decisions going forward.

And money is so important. I always look at money management as one of the two things really keeping people with disabilities separate. And that's money management and relationships. But we can't have independence. We can't have community integration without money management.

It's not just enough to live in the community instead of an institution. It's how you live in the community. It's about how you take part in the community, including the financial sphere, how you manage and spend money in the community.

And the problem from before is the same, is that people with disabilities are often shut out of the financial realm because they're not allowed to have money. If people with disabilities are on benefits, if they're receiving that Medicaid, that social security that keeps them healthy, that keeps them living in the community, they are limited in the amount of money they can have. That fiscal cliff of \$2,000, that can cost you the things that you need to stay healthy and stay living in the community.

And that's why I want to talk to you about a thing called ABLE, the ABLE Act and how supportive decision making can help people have money, manage money and save and spend money ABLE stands for the Achieving a Better Life Experiences Act. We just call it

ABLE. What the ABLE Act is, it sets up special accounts. If you've ever heard of a 529 account for education where you can put money away for a loved one, it grows tax free and can be used to pay tuition. Other expenses, I want you to think about that able as a 529 for life. And the way it works is I or my friends or my family can put up to \$18,000 a year into an ABLE account and that money grows tax free and it has no impact on my benefits. It does not count against that \$2,000 that would cause me to lose my benefits. So \$18,000 a year, I can earn it, I can receive it, someone can give it to me and it grows tax free. And as long as it is less than \$102,000, it has no impact on my benefits. If it goes to \$102,000 SS, I would be suspended but my Medicaid would stay. So what an ABLE does is it gives people a chance to have money without losing their benefits. You can learn a lot about ABLE from the ABLE National Resource Center, their websites on your screen, www.ablenrc.org. ABLE National Resource Center.org. They have all kinds of good information about ABLE, how to open an ABLE account, what it can involve.

But what you should know about ABLE is if you are receiving benefits, you can be eligible for able. If you would receive benefits but haven't applied and some and a Doctor certifies you would be eligible, you can open an ABLE account. So ABLE is for people who are on public benefits, SSI, SSDI, Medicaid, et cetera, or who would be eligible for them if they applied. And in those cases you can create an ABLE account. What you see on your screen is a bunch of tiny LED tiny words. The reason they're tiny is these are all kinds of things you can use ABLE accounts for. You can use ABLE for just about anything. You can pay for education like tuition, like post-secondary education like books. Pay for housing, rent, mortgage, home improvement. Pay for employment expenses like job training, like assisted technology, healthcare expenses, transportation and life necessities. And that's a huge one because you can pay for things to help you have a life including a vacation because people with disabilities sometimes like to go on vacation, they like to go to the beach too. So what Enable does is it gives you the freedom to have money like everyone else without having to worry about losing your benefits.

And it does one more thing. I think it provides a pathway for some people it's a way out because that \$2,000 fiscal cliff can be a life sentence of poverty as one person called it because you can't work and earn really good money, but ABLE can help you do that. And the story I'll tell is a young woman I met in Indiana who was afraid to work but she opened an ABLE account, got a minimum wage job, kept her SSI, um, and she made some money in that account, that job put it in her able account, took some out to pay for transportation and job training, which helped her get a better job to earn more money, which she put in her ABLE account, which she took out to pay for additional education and um, ways to help her become a better employee, which she used to get a better job and earn more money. The last I heard from her, she was not on benefits anymore 'cause she didn't need them. She

had a full-time job with benefits. So ABLE can be a pathway to not needing those benefits and having the freedom to have as much money as you want.

So I always recommend looking into ABLE. And the other great thing about ABLE as opposed to um, special needs trust, which you might have heard special needs trust do much the same thing as able except with one difference in a special needs trust, there is someone who controls the money, the trustee, someone who's gotta be paid to manage the money. I would have to ask the trustee for money to buy something. In an ABLE account, the person with a disability, the person who has the account decides how to spend the money, has to respo, has to manage the account has to decide what to put in and what to get out and what to spend their money on.

Because the whole point of ABLE is to help people have better lives, to be more independent, to have a better quality of life.

Which is what self-determination has been shown to do. So ABLE accounts are all about self-determination. They're all about making decisions. They're all about deciding how to spend your money.

And isn't that a great opportunity for supported decision making? In fact ABLE accounts, many of them allow you at the front end to identify people who can help you manage the account and you can give them different levels of control. Maybe I just want someone to know how much money is in my ABLE account so that they can, if they think I'm overspending, talk to me about or, or I can talk about budgeting with them. Maybe I wanna give them money to put money into my account. Maybe I want my mom or my dad to be able to contribute to my account. Maybe if I'm just learning how to make decisions, I want mom and dad to be able to take money out to be able to help me until I am ready to make my own decisions on what to put in or take out.

That's what supporting decision making can do. It can provide that freedom. And I talk about, I mentioned this when the, the power of attorney, a growth clause where whatever you are doing, whatever plan you have, look at it every year, every year, take a deep dive and decide whether it's working. People come into and out of our lives, issues change. Things change. We should change with them. We should make sure that we are able to make decisions that we have the support we need for the things in our lives. Every year, every power of attorney, every vocational rehabilitation plan, every waiver plan, every life plan. Dig deep every year and decide what support you need to make that work.

Couple of things before we leave, um, the elephant in the room, uh, safety. I get this question all the time, Jonathan, can you guarantee that if I do this, nothing bad's gonna happen? Uh, I'm not gonna get ripped off. And the answer is no, I can't. In fact, what I can

guarantee you is someone out there with or without a disability is getting led astray by someone they trust. Uh, but if that's the standard, you can never make a mistake, then all of us need guardians because all of us make bad financial decisions. All of us make bad life decisions. If you don't believe me, if the standard is never make a mistake, I hope you never drink a beer. I hope you never lie in the sun. I hope you never get bluffed out of a hand in poker. All of those were bad decisions, but they're part of making us who we are. But at the same time, I think about Dr. Kemp's studies when she found that people are safer, they're better able to avoid abuse when they have more self-determination. And I say this, if I have a choice between two things where I can get taken advantage of, and unfortunately there are horrible stories about guardians taking advantage of people with disabilities doesn't mean that guardianship's bad or that all guardians are bad. It means that some people are bad. So if I know that I could get hurt in either situation, I'm gonna start with the one that builds self-determination because that's correlated with safety.

And if we focus on that supported decision making happens, that person on your screen is Jenny Hatch. We mentioned her earlier. She was the first person to win a trial to get her rights back. I was honored to be there. She's using supported decision making right now to live her life. It's been 12 years since her trial and she's as happy now as she is in that picture.

And since her case, at the time of her case, no states had supported decision making laws since then. Texas was the very first state to have one and New Mexico just became the 30th. So I say this with amazement and honor that Jenny Hatch changed the world. That supported decision making, that saying to people you can do things, change the world, not settling for 1500 years of the Justinian code, change the world.

But we only change the world if we recognize that rule. One, we recognize, respect and honor everyone's right to make choices to the maximum of their ability. Like I said, it doesn't mean there should never be a guardian, but it does mean that we can do better for people and that some people don't and that those who don't can have the opportunity to make their own decisions.

And we can use supported decision making in all of the ways I talked about in medical care, in education, in employment, in life planning. Today was just about finances. But finances are so important in our lives.

So if I've intrigued you, if I've helped you see that there can be a way to make decisions. Use it. Use it in your life. Use it in the lives of people you care about. Find ways to use it. Find ways to give people with disabilities the same opportunities for success in security as their non-disabled peers. Changing the culture that has existed since Justinian will change the

world for people with disabilities and for us, for people who are lucky enough right now not to have disabilities, we're all one second away from having a disability. One slip, one fall, one diagnosis, one stroke or heart attack. You're all one second away. So unless you're lucky enough, and I say lucky in quotes, lucky enough to die suddenly, someday you are gonna be, if you're not now, a person with disabilities. You're gonna be in the system and ask yourself what type of system you want to be in. One that respects your abilities, one that protects your rights, or one that's just followed the process of Justinian. And that assumes you can't do anything. I think I know the answer. So if you're a professional for the people you work with, if you're a person with disabilities for yourself, if you're a family member for people you love, we can do better. We can change the world. We can empower people.

It would be my honor to do it with you. Thank you so much. I'm happy to stay as long as you want and take questions. I'm mindful that we're at one o'clock, but I can stay and answer any questions you would like to have. What can we talk about?