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SELF‑EMPLOYED AND SELF‑DETERMINED:

GUARDIANSHIP IS NOT YOUR ONLY OPTION WEBINAR

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(Recording in progress)

NIKKI POWIS: Welcome, everybody. Self Employed and Self Determined is obviously a topic of interest to many because we have quite a lot of people signed up. So appreciate that. Feel free to pop in the chat where you're from, where you're joining us from. Always nice to see where you are coming from. But with though, my great pleasure to actually introduce our speaker today. So, Jonathan Martinis, he is the Senior Director for Law and Policy at Burton Blatt Institute at Syracuse University and he leads efforts to ensure that older adults and people with disabilities have the access to the services and supports they need to live independent and inclusive lives.

Jonathan's led Supported Decision Making projects all across the US, has educated and trained 10s of thousands of older adults, People with Disabilities, professionals across the country on Supported Decision Making, theory and practice. He has written and co-written over 60 publications on Supported Decision Making, including the first textbook and theory to practice guide book on the subject.

So, thank you, Jonathan, for taking time to be with us today. I will turn it over to you, and thank you so much.

>> JONATHAN MARTINIS: Thank you so much, Nikki, and thank you everyone for joining us today. What we are going to talk about today is my favorite subject. What I think is the greatest advance for humans in Civil Rights for People with Disabilities since the Americans with Disabilities Act. We are going to spend the next hour talking about Supported Decision Making.

If you have heard of Supported Decision Making, you have probably heard about it as an alternative to guardianship. Something you can do instead of going into guardianship, something you can do to get out of guardianship.

And that's true, and we will talk about that. But there are two things I think are important that we understand from the beginning. Because while we are going to talk about Supported Decision Making as an alternative to guardianship, I am not here to tell you there should never be guardianships. That is not my intent. I am not here to tell you that if you are a guardian, you're somehow evil or if you recommended guardianship, you did the wrong thing. Etc. What we are here to talk about today are options.

Options that may be able to improve people's lives, including help them become self employed.

And what I want to make sure we have happen today is you have all that information in front of you, when it comes time or if it ever comes time for you to make that difficult decision. So, that's is my first promise.

My second promise is this. Everything we talk about today will be backed by one or two things. Law or Science.

We are not talking about aspirational goals or hippie trippy vapor wear today.

We are talking about time and scientifically tested methodologies that have been shown to improve the quality of life for People with Disabilities.

So, with those two things in mind, let's begin. And let's begin by thinking about something that people don't think a whole lot about. Or don't have the opportunity to. And that's their this, their rights.

People dont really think about their rights. I know you know you have rights. But I want you to really think about the ones that are important to you.

The ones that make you feel the proudest, the strongest, the one that you would fight to keep, the ones that truly make you feel like a citizen, an American.

A human being with Human Rights. Is it something like Freedom of Speech? Or Freedom of Elections?

Or freedom of religion.

[audio interruption]  Nikki if you wouldn't mind muting everyone.

Or is it the right to life, liberty and the pursuit of happiness? Now with that in mind, think about what all those rights have in common. Think about Freedom of Speech and

Freedom of Religion. What do they all have in common? They all have choice in common. Every right we have comes down to choice. Everything we that do comes down to choice. Freedom of Speech, the right to choose, what to say, and what not to say. Freedom of Elections, is right to choose who will govern us. Freedom of Religion, is the right to choose how, where, and even whether we will worship.

That is what freedom of choice means. So, if you ask me what my favorite right is, my favorite right is the right to make choices. Because choice makes everything we do possible.  Choice makes everything we do real

Without choice do we even have rights? And when you hear me talk about freedom of choice and the right to make choices, I'm gonna throw a buzzword at you, I'm not a huge buzzword guy

But I want you to think about this one. Its called Self-Determination. In fact its in the title to this presentation today.

What self determination means is making choices. When people are self determined, they do things, instead of having things done to them. They make choices instead of having people make choices for them. When people are self determined, they are what is called the causal agent in their life, the people making things happen, the person making choices.

So, when you hear self determined, I want you to think of it this way. People who are self determined make more choices. Here is something we know, and we know this from 40 years of research. For People with Disabilities, particularly people with Intellectual and Developmental Disabilities, those who are more self determined, who make more choices, have demonstratively better lives.

We have seen from study after study going back to the 1980s, that People with Disabilities who are more self determined are more likely to be healthy, independent, more likely to be involved in their communities. More likely to be healthier and safer. And here is something else that is incredibly important. It gives us the title of this presentation. People with Intellectual and Developmental Disabilities who have more self determination are more likely to work.

They are more likely to make more money. They are more likely to be involved in managing their money and their lives. So, it is absolutely fair to say, that based upon decades of studies, self determination, making choices, is the key to a good quality of life for People with Disabilities. But with that in mind, ask yourself another question. Those rights that are so important to you. Freedom of Speech, freedom of election, Freedom of Religion, are they worth anything if you are not allowed to use them? If I say to you, Nikki, you have Freedom of Speech, but you are only going to talk when I tell you to And you're only going to say is a what I tell you to, or you have the right to vote but you will only vote for who I tell you to, and that is only if I take you to the poles to vote. In those situations, are those rights?

When you have a choice taken away, do you even have rights? That is exactly what we have been doing to People with Disabilities for about 1,500 years.

A quick confession for you. I am something of a legal geek. I say that with some pride.

What I can tell you, in the western legal tradition, the very first time all of the laws across an entire country or empire were put together in one place and harmonized was the Roman Empire about 1,500 years ago. An Emperor named Justinian had all of the governors from all the provinces got together and harmonize their laws so the laws would be uniform from one part of the empire to the other. They put it into a book and that book is called the Justinian Code. I am such a geek because I have, one, a copy of that book. And, two, named one of my sons Justin.

The first time we had laws and rights that were harmonized, really the first time we had enforceable rights, one of those laws said, if you are feeble minded, and that was their word for People with Disabilities, feebleminded, you had to have people over you making decisions for you. You had to have what they called a curator. And that began what I would call a culture or expectation that anyone that shows or needs any help, it is expected they will not be able to do things. That they should not be allowed to do things. That expectation and culture has followed us ever since. In the British Empire, where we got most of the laws, they updated Justinian in the Middle Ages. They said if you are an idiot, or lunatic, and that was their word for People with Disabilities, you had to have a committee over you, to make decisions for you, to do the things for you, taking away your self determination and here in America we just call that guardianship. Some states call it conservatorship.

I'm going to use guardianship all the way through. Because here's the thing, even though every state has their own laws, guardianship or conservatorship they work basically the same in every state. If a judge decides that I cannot exercise some or all of my rights, what that judge is supposed to do is to take away those rights that I truly cannot exercise, those things that I truly cannot do and give them to someone else.

Someone else then becomes my guardian. They get the power to do what I cannot.

Just what I cannot. If guardianship worked that way, you would have no bigger fan than me. In fact,  I have nothing against guardianship when its needed. My godson is in guardianship and thank God for it, because my sister empowers him. But here is again what we know from studies. We know that even though guardianship is only supposed to be used to take away rights that you can truly not exercise, well over 90% of guardianships are called full or Plenary and take away all rights. Regardless of weather you are able to exercise them, regardless of what you want, regardless of what you can do or what your doctor says, As I've had judges tell me across this country, as long as you're allowed to take away all the rights, to call it plenary guardianships, courts are going to prefer that. Because its easier to check all the boxes than it is to figure out which ones to check. Does that mean guardianship is wrong? No. It means we have to be careful. Because when we take away rights that people don't need to lose, when we take away rights that people are able to exercise, bad things can happen.

As these two journals have said, when you have a guardian, you have a third party, often a stranger who has the power to decide what kind of life you have, even going into the most basic, personal, intimate decisions, where you live, who you can date, weather you can work, in the hands of a stranger. Imagine saying I want to work, I want to have my own business, and someone is saying you are not going to, simply because they have the power to do so. How would you feel? How would you feel if you knew that you could work, if you wanted to explore work and someone said, no, I am not going to let you do that.

That kind of taking away of people's right to make choices, the removal of self determination, is harmful. We know from studies going back to the 1970s that when People with Disabilities lose their self determination. When their choices are taken away, their lives get worse.

One study found people losing the right to make choices feel helpless and hopeless, and self critical. Another found that people who have less right to make choices feel more passive, they have lower self esteem, they feel inadequate, they have less ability to do things.

That is not rocket science. Is it? If I tell you time and time again you cannot do something, Are you feeling particularly motivated to try? Of course not. That is something that is called learned helplessness. That is something that has been documented, where people told they cannot do things will see it as a personal failure, and then will not attempt new things, because they don't want to fail at that, too. That does not mean that guardianship is bad, evil or wrong, it means you have to be careful before we put people in guardianship. It have to be careful and think if that's the right thing to do.

Think of it from an employment standpoint. If you are a bank and someone under guardianship asked for a loan or to open up an account, would you let them? If they don't have the right to sign a contract or sign a check, would you be willing to give a person an account or would you be willing to write them a loan?

If you were a business, would you enter into a contract with another business whose President had no right to sign contracts? If you were an employee, would you work for someone that doesn't have the right to sign checks or has been found to be quote unquote incompetent. Of course you wouldn't.

So, that means we have to be extra careful when we are dealing with guardianship, because if it is not right, people can get hurt by it. That is something we have known about for decades.

Let me tell you this. Problem and concerns with guardianship did not begin with free Brittany. We have known since the 1980s of the dangers of guardianship. What's on your screen is a quote from Congress.

Congress did their first investigation into guardianship in 1989. So 30 almost 5 years ago. They talked to people under guardianship, talked to guardians, did research, looked at guardianship statutes and what you're looking at on your screen is one of the first findings from the Congressional report. Take a look at it with me. Look at the bold words.

The typical ward, person under guardianship, has fewer rights than the typical convicted felon. And, again, imagine being a Person with Disabilities and being told that people in jail have more rights than you do, when you have done nothing wrong.

When there are guardianships, particularly what I call over broad, and undue guardianships, guardianships that take away more rights than people need to lose them or take away the rights in the first place, when people are able to exercise them. When you have this other person, a guardian, often a stranger, who can decide where you live, what you do,  what kind of life you lead,whether you work, what kind of healthcare you get, as the Congress said, sometimes when you die.

As they said, in one sentence the most punitive civil penalty that can be leveed against an American citizen. The rest of that sentence, "short of the death penalty". So, where do we go from here? I made you a promise when we began. I'm gonna keep it. I am not here to say there should never be guardianships. Absolutely not. Absolutely, there are times when guardianship is appropriate. When a person is so limited in their abilities that they cannot take part in their decision making process, of course they need a guardian.

When a person has limitations and does not wish to take part in the decision making process and is putting his or her health at risk, of course guardianship is appropriate. In emergency situations, when there is no-one available to help, a temporary guardianships is a fantastic temporary solution. I am not here to say there should never be guardianships, but what I am here to say is there should never never never be guardianships just because you have X diagnosis, or you are Y years old, or because you need help. And the two on the bottom that make me nervous and turn my stomach because I hear them so often. 1, because that is the way it has always been. And, 2, for your own good. I hear that one at the bottom across the country. It is for my son, my daughter, my mother, my brother, my family whoever for their own good. If I do not get guardianship over this person, something bad might happen, they might make a bad decision.

They might do something they shouldn't do, or meet someone they shouldn't meet or they might sign something they shouldn't sign, therefore we need to have a guardian for this person's own good. I never question people's motivations. Because, while it is true there is some guardianship abuse out there, I have found that 99% or 98% of cases, it is just someone who means well. A mother, father, loved one, who is looking out for someone they care about, and who thinks this is the only option.

So, that is why I hear, it is for your own good. And people mean well. But I have learned this. And there is a quote up on your screen saying it. This quote is pushing a hundred years old, by the way, from the US Supreme Court. They say this. When we mean the most well, that is when we have to be the most careful. Because when we act without thinking, when we act with assumptions, bad things can happen. The greatest dangers to liberty lurk in the insidious encroachment by men of zeal who are well meaning, but not without understanding. Look, there was almost 100 years ago.

And that was the Supreme Court. They didn't know women could have zeal. They were nine old white guys talking amongst themselves, we've come a little bit since then, we understand everyone can have zeal. So, consider that sentence meaning that people who mean well can do bad things when they don't understand the possible consequences or when they dont understand the 40 years of research that says taking away self determination when it is not needed can out real harm. Yet, I still hear it. For your own good. They might sign something they shouldn't sign, do something they shouldn't do, or meet someone they shouldn't meet. Then I ask them to their about their lives, the same I'm going to ask you.

Think about your life. Think if you have ever closed on a mortgage or signed a lease. If you have, you have done what I have done. You have gone through a ceremony, they call it, where you get the papers and sign the paperwork. What is that? That is ceremony, if its done real real or virtual, you have a stack of papers going up to the ceiling. Real or PDF, they are theoretically this high and one by one they are given to you and you are told,

sign here. I ask. Were you like me? Did you sign them without reading them first? Because if you were like me and the majority of people, think about what you did. Think about what a horrible decision you just made. You just put hundreds of thousands of dollars of your money and 30 years of your life into the hands of a bank, and you did not read the fine print. What a horrible decision. I think you need a guardian. Or, have you ever had surgery or had to consent to a medical procedure. I know I have. About eight years ago I had to have my knee done. I am a huge baby when it comes to medical care. They wheel me into the surgery center and my heartrate is jacked. I am just hoping for Valium at that point. And what's happening is a bunch of strangers are getting up in my face speaking jargon, I'm your doctor, I'm your nurse, I'm your anesthesiologist, I'm this, I'm that.

And what they all have are pieces of paper that they are shoving in front of my face and they are saying sign here. Now, are you like me and signed them without reading first?

If you were like me, you did a horrible, dumb thing. You put your life in the hands of strangers. You probably signed away your right to sue, and instead lead to arbitration.

And you didn't read the paperwork? You made a horrible decision; you need a guardian.

Now here we are, thank god I hope, coming out of almost four years of pandemic, and I wonder if any of you have played my favorite pandemic game, because yes, I had a favorite pandemic game that got me through the hard times of the pandemic. Let's see if you maybe did something similar.

My game went like this. Have a bunch of drinks and see what shows up from Amazon. I tell you, I could tell what kind of day I had by what Prime delivered to me the next day.

I knew if it was a pasta maker, I was stress eating. I knew if it was a useless piece of workout equipment, I was stress eating. Often I got the same at the same time. If you did this, if you did retail therapy, what a horrible decision. You signed things you shouldn't have signed, ordered things you shouldn't have ordered and bought things you shouldn't have bought. You need guardians. And I ask people this.

Have you ever had a bad relationship that taught you what a good one is? Have you ever been a rescue

buddy or been a rescued by a buddy or woken up after a really interesting night and said, wow, I am never going that again, but I am kind of glad I did, because now I have a story I can tell. We use cliches we use about the day after, a teachable moment, a life lesson. We all talk about those.

Well, if you did that, doesn't that mean you did something stupid you will not do again. Doesn't that mean when you dated the wrong person you can't be trusted to have a good relationship and you shouldn't be allowed to date again? The answer is, of course not.

Because the mistakes you made, the teachable moments, the bad relationships, the misjudgments, they taught you who you want to be, and who you don't want to be. They taught you what to do and what not to do in the future. They shaped you. Our mistakes make us who we are.

So when we say, about people in our lives, they need a guardian for their own good, aren't we saying they dont have the same right to grow that we do? Cuz let me tell you, your mistakes made you a better, stronger, smarter, more contributing member of society.

If we take away that ability from people who could exercise it, who could benefit it, aren't we taking away people's right to be people. I will give you one more example. I want you all to think about the year 1995, and I am sure there are people on this call who weren't alive in 1995 or don't remember it because they were very young. We all hate you. Everywhere who is old enough to remember 1995, think about it. Think about what life was like for People with Disabilities in 1995. Because 1995 was only five years after the Americans with Disabilities Act was passed. It was four years before the US Supreme Court rendered its decision in a case called Olmstead, that said people have the right to live in a community. That means in 1995 you had the absolute right to tell people with disabilities you will live in an institution. It doesn't matter what you can do, what you can't do, what you want to do. If we want you to live in an institution, you will. That was 1995.

1995 sheltered workshops where people who were perfectly able to work, were instead, put to work for sub minimum wage, in places that only worked with People with Disabilities, in secluded areas. They were the expectation. People would brag. Vocational Rehabilitation in schools would brag about the number of people they placed in a sheltered workshop.

In 1995 we didn't have services and supports like we do now. Technology like we do now. 1995 wasn't that long ago. Its only 28-29 years, right?

This about how far we've come. At the dawn of 2024, we know that People with Disabilities have a Supreme Court protected right to live amongst their fellow citizens. If they can live in the community and want to live in the community, they should be empowered to live in the community, same as everyone else. Sitting here today in 2024, working in the community, paying regular taxes, making regular wages, is an expectation. Someday I hope to say it is a right. Sitting here today, we have supports, services and Medicaid Waivers, we have technology. Consider your phones, the one's that I hope you're not playing with right now. But consider your phones and what you can do with them.

You spent significantly more time on your phone not talking than you do talking, With your phone you can refill prescriptions. With your phone you can make an appointment, have a Telemedicine appointment, and if you want to, you can even conference a person in to help the doctor understand you and you understand the doctor. With your phone you can check your bank balance, balance your budget, and give someone else, if you want to, access to your bank records to help you budget your money. With your phone you can set reminders to refill prescriptions, you can connect with people to help you access the things you need to do. A quick story. I worked with a woman with Traumatic Brain Injury and diabetes. When she suffered her brain injury, she began having difficulty managing her diabetes. She had a couple of crashes.

She is exactly the kind of person who would be in an institution in 1995. But do you know what she has now? She has a free app that connects her phone to her glucose monitor, so when her blood sugar is low, she gets a text to eat something. If it continues to get lower her mother, sister and doctor get texts so they can intervene. Just like that! For free, mind you, this person is able live and work independently in the community. What I am getting at, right now, in 2024 we have more ways to make more people more independent than ever before. That is undeniable, right? We have more ways to help people do more things, live better, feel better, act in a more integrated and inclusive way. But answer me this stupid question. How come the number of people under guardianship has tripled since 1995? Tripled. In 1995 there was an estimated 500,000 people in guardianship. Today that number ranges from 1.5 million to 1.7 million.

And before you say it is because we are getting older, and believe me, every day I get up and something else aches and pains, I know we are getting older, but what the National Council on Disability found, the fastest growing segment of people going into guardianship are 18 year olds, 18 to 24 year olds with Intellectual and Developmental Disabilities, because somebody meant well. Someone said you have no choice, you have to get guardianship, you have to do that.

And just like that an 18 to 24 year old has the best opportunity to learn things. Someone has a tremendous opportunity to learn and grow has had all their rights taken away, statistically, for the rest of their lives, and the science is scary. We know that people under guardianship, particularly under guardianships they don't need, can have a significant and negative impact on their physical and mental health. They can live less well, do less well, feel less well, and function less well.

On the other hand, we know from study after study that People with Disabilities who have more self determination, have a better quality of life. They are more likely to be independent in parts of their community, more likely to work and earn more money.

And the number one reason I hear for guardianship across this country, and I'm fortunate to have gone across this country talking about this, is safety,

Someone saying if I don't get guardianship, my son or daughter might be abused. And, again, I never question a parent's motivation. I have two sons. My first motivation is to keep them safe.

But what I do talk about when someone says I have to get guardianship for safety is science. There is a study up on your screen right now. Its part of a series of studies done by a Professor Ishita Khemka out of Long Island University. What Dr. Khema looked at a link between self determination and safety. And what she did was she worked with a cohort of women with intellectual disabilities. If you don’t know this you should.

Women with intellectual disabilities are exponentially more likely to be abused and neglected than other segments of the population. More likely to be physically abused, mentally abused, sexually abused. It is horrible. So what Dr. Khemka did, she worked with women with intellectual disabilities, and I am no scientist, so I call it an apples to apples study, meaning that everyone in that study had similar abilities and limitations. What she did was a classic experiment. She divided them up. She said to one half go live your lives and to the other half she gave them access to a curriculum designed to enhance self-determination, to teach them about decision making, to give them opportunities to make decisions and to let them know they should make decisions. When that was done, she gave them a test, a recognized, vetted test designed to examine how well people can recognize potentially abusive situations and avoid them. Here is what she found. Apples to apples. Those with more self determination were found to be, across the board, better able to recognize abusive situations and avoid them. They were safer. Again, I say, is that rocket science? If you know something is yours, if you know its your body, your life, your stuff, if you know that belongs to you, aren't you going to fight like hell when someone tries to take it away?

I have told judges, parents and professionals this across the country. If you want to keep people safe, don't take away their rights. Build their abilities. We have this fallacy that if we just put people in guardianship they will be safe. Like it is Rapunzel in the tower. Like if we put her up there, she will be perfectly safe. Well, news flash, Rapunzel got out. That is the plot to the movie tangled, if you are born after 1995. What happened, Rapunzel got out and she met someone. If we take that as a given that you cannot envelope someone in a bubble, that guardianship is neither a suit of honor nor chastity belt, shouldn't we be empowering people with the knowledge and skills to be safe as opposed to simply hoping that they will be safe because they won't go anywhere, do anything, or meet anyone.

I know the one I would choose. So, the other thing is this, and I call this the cherry on top of the sundae. The National Core Indicator Study, which geek that I am, is my favorite study, the National Core Indicator Study was done in almost every state in this Country. It is an examination of quality of life for people with Intellectual and Developmental Disabilities. It is, again, an apples to apples study. They looked the old words: mild, moderate and severe disabilities. So they compared the experiences of people with mild disabilities to people with mild disabilities, moderate to moderate, and severe to severe. And what the entire point was, was to look at the impact on certain things on quality of life.

One of the things they looked at was whether or not a person had a guardian, and in every state, this was done in, what was found was this: apples to apples again, remember. People without guardians were more likely to work and make more money, more likely to live independently, more likely to have friends other than their family and staff, more likely to date and socialize in the community, and more likely to practice the religion of their choice. So I talk to parents about this study, what I do is I put this slide up there and say this, isn't this exactly what you want for your child? Or if you are a professional, isn't this exactly what you would want for the people you work with? And if you knew that the one thing that could be standing in between having this and not having this was having a guardian, doesn't it mean we have to think about it first. That 1,500 years since Justinian, of reflexively assuming that people need guardianships are more than enough. Oh, yeah, by the way, they did that study again a couple years later and they found the same thing. A few years later they found the exact same thing. Apples to apples. People with Intellectual and Developmental Disabilities who did not have a guardian were more likely to have their own homes, their own jobs, more likely to be part of the community, active parts, more likely to date and get married, more likely to be respected.

They did it again more recently, they haven't published the results, but I know the people who did it and spoiler alert, they found the same thing again and its not rocket science. They had more self determination.

They had more opportunities to make choices, they were able to make more choices and it translated to a better life.

So, where can we go from here? I just spent 20 minutes, and I am hoping you are not regretting being on this Webinar, but I just spent 20 minutes talking to you about the impact of self determination on the quality of life. So, what I am hoping I taught you is this.

That self determination is the key to a better quality of life, and the converse is true. Losing self determination can make people's lives worse. Well if we accept those two things and I think we have to because 40 years of studies say so. There is one more thing we have to accept. And that's this, people need help. I mean everyone needs help. You should have seen me trying to get on the Webinar, I had to register, I had to figure out all these things. It took me forever to get on.

But People with Disabilities often need more or different kinds of help perhaps than other people. So self-determination is not "you're on you're own. Vaya con dios, live your life." Absolutely not, because people need help.

Here is what I am proposing to you after 20 minutes of this Webinar. What we need to do is find ways to maximize People with Disabilities' self determination, because that is the key to a better quality of life, while at the same time making sure they have access to the help they need to exercise their self determination, to make choices, as effectively and safely as possible. And if we agree with that, we can move forward.

Because what I can talk to you about is Supported Decision Making. Yes, I know we are on slide 27 and I am finally getting to the point. But what Supported Decision Making is, is a way to enhance and empower both self determination and help. If you want to know what Supported Decision Making is, there is a great definition on your screen. We can read it together.

Supported Decision making is a recognized alternative to guardianship through which people with disabilities use friends, family members and professionals to help them understand situations and choices they face so they may make their own decisions without the need for a guardian.

Google scholar Supported Decision making and you'll see those long words. Its in textbooks, its in studies.  I wrote it so you have a chance to say you're listening to the guy who wrote that definition.

But if I had my druthers, I'd prefer you forget it because it is crap. This definition stinks. This definition is pseudo intellectual, intellectually insecure crap. If you want to know what Supported Decision Making is, ask yourself a question, how do you make decisions? What do you do when you don't know what to do? What do you do when you are faced with a situation you have never seen before? What do you do if the doctor is speaking jargon to you?  What do you do if the auto mechanic is speaking jargon to you?

What do you do if you're faced with a situation in your life or at work or in a relationship that you have never seen before? What you do is you get help. When the doctor speaks jargon, if you are like me, you say can you please explain that in plain language like I'm a 3 year old. If the auto mechanic is talking gibberish at me, I have a buddy who knows about cars and I ask him for his advice.

When one of my children is getting in trouble on days that end in Y, I have a sister who's an educational professional, who I seek out for advice. My other sister is a gerontologist, who has been remarkably helpful now that my mom is getting older.

So, what I am getting at is this. Supported Decision Making is nothing more and nothing less than getting the help you need to do the things you need to do to make the decisions you need to make.

In other words, it is how we all live our lives. Every single one of us uses Supported Decision Making every single day. Its just that people without Disabilities, and by the way I call People without Disabilities, are TABs, or temporarily able bodied. Cuz each and every one of us is one second, one slip, one fall, one diagnosis, one heart attack, stroke or bad driver, away from having disabilities. So if you a temporarily able bodied person, understand this, you use Supported Decision Making every day. You don't call it that. But you call it making decisions. Think about all the cliches that we have about Supported Decision Making. Don't go off half cocked, don't make a snap judgment, get a second opinion. My dad would always say if you measure twice, you only need to cut once. They all mean the same thing. Get help. Get a second opinion,. If you are professional, you are judged on your job evaluation, by how well you work with others. How well you collaborate, how well you seek assistance. So people without disabilities using Supported Decision Making is a sign of wisdom, it is a sign that you are doing the right thing, that you are getting a second opinion. But for People with Disabilities, ever since Justinian, if someone has the gall to say I don't understand, explain it to me, what's happened to them for 1500 years, is society has decided they cant do things.

They cant make decisions and therefore they should not be allowed to make decisions and therefore we see all of the scientifically proven negative impact of the loss of self determination

So where can we go from here? Where can we take decision making to use it to serve as an alternative to help empower people to help them reap the benefits including enhanced employment that come with self determination.

Well first things first. Just about every state law says the same thing. They all say that if a person is incapacitated or incapable or unable to make a decision, or guardianship is necessary, its always some word like that. People who are incapable or unable or incapacitated, incompetent. Where guardianship is necessary to help them, or there are no less restrictive alternatives available, check your State law, it will say something like that.

Think about this. What does that mean? What does it mean to be capable? What does it mean to be able? What does it mean to be competent? And realize this, something that you already know. Being capable and competent and able is not a yes and no question. Because each and every one of us is competent and capable and able in different ways at different times.

You ever wake up one day not feeling well and say man I better not do anything important today? I am not thinking straight. Ever been too close to an issue and as my boss says, you have too get to 30,000 feet before you deal with it?

Do you realize that what makes you capable, there are things that you can do right now that I can't. There are things that I can do right now that you can't. And there are things that none of us can do unless we get help. You want an example? Unless you are a medical professional, you are a doctor, a licensed practical nurse, unless you are someone who is able to diagnosis, treat and prescribe, you can't take care of your healthcare, because you can't diagnosis yourself, you can't prescribe yourself your own medication. That means you have to get help, you have to go to the doctor, You have go to the professional, you have to go to the pharmacist. That is the person that empowers you to manage your health. Yes, of course I have the capacity to take a pill, but I am not feeling well, I go to the doctor, I am a big baby, I kiss the doctor's ring and say please make me feel better.

The doctor writes a script. And yeh, I am perfectly capable of taking that script. But let me tell you something, I have no idea what's in it. I don't know the difference between Erythromycin and a Z Pack.

I don't know why the doctor prescribed one and not the other and I am not reading that tiny fine print on the bottle. Does that mean I am incapacitated or incapable of taking care of my health? No. It means that I needed support from the doctor, from the pharmacist, in order to exercise and take care of my health. So, what I tell people is this. The smart questions. If you are talking about employment, self-employment, if you are only able to manage your business, if you are only capable to run and be self employed, if you need help, are you incapacitated? That better not be a yes. Because that would mean we are all incapacitated, because if you are running a business, you're self employed, you may need a ton of help. You may need an accountant, tax professional, attorney, you're certainly going to need employees.

You need tons of help to manage your business.

So, if you are incapacitated just because you need help, my God, we all need guardians.

Which means there is another question we have to ask. If you can manage your business, be self employed, manage your financial decisions, when you get help, when you have someone helping you with the bank, when you have someone balancing a budget, is a guardian necessary?

Of course not, because you are able to do the things you need to do, with the help you need to do it.

Which means we have to ask the most important question. If you are considering guardianship, if you are thinking about whether a guardianship is appropriate or necessary, we have to ask this question.

What else have you tried? You cannot decide that 99% of the time yes, a person in a coma needs a guardian. But 99% of the time you cannot know if a person is incapacitated unless you have tried something to make them capable. So, what have you tried? Have you tried Supported Decision Making, have you tried other options. I beg judges, and I have gone to judges across the country in cases and said, judge, how do we know? How can we sit here today and assume given all the services, all the supports, all of the technology that we have now? What else have you tried? That is my dream.

That there will be a guardianship case where its uncontested because the person has no idea he or she has the right to fight it. Because a parent or someone hired a lawyer and the lawyer wrote up the order, typical boiler plate language, and gives to it the judge and the judge says wait a second, before I sign this, can you tell me what else you have tried? Because the law says we have to make sure it is necessary. How do you know it is? That is not just my position, that is the position of the National Guardianship Association. The National Guardianship Association is made up of guardians, by guardians, for guardians. Their website is guardianship.org. They regulate guardians, they train and certify guardians. There is nobody more invested in guardianship than the NGA.

And this is what they say. Before guardianship, try something else. Try Supported Decision Making. It might work, it might not. If it doesn't work, guardianship may be appropriate, but what is the rush? Think about the rights that are so important to you that you would fight to keep. Aren't they worth slowing down a second to see if the person could exercise them if they had some help. And here's the thing, Support Supported Decision Making can do for people with disabilities precisely what it does for People without Disabilities. It may be different methodologies, it might be different methods. But it is the same idea.

Think about the way you use Supported Decision Making when you go to a friend for help.

Your friends help you narrow down your options. They help you get to 30,000 feet and see the forest for the trees.

They help you do a pro or con list, Or make sure you're not acting emotionally rather than rationally. You can discuss with your friends, you can I call it the war game with your family and friends and supporters, so that when you make the decision, you are sure the decision you are making is informed. It is your decision from all the information you have before you.

Now, you are probably thinking, because most of the people I talk to do, okay, we are pushing 45 minutes in. So hippie. Get to the point. How do I do it? What is Step 1, Step 2, what's the book, what's the app?

What do you do. I have good news for you. There isn't one. In fact, I have written two books on this subject.

And if anyone ever says this is the one and only why way, if you do these three things you are doing Supported Decision Making, run away. Because you already know the answer. You already know that you get support and use it differently than I do. There are things you need support to do that are different from where I need support. So, you need to find what works for you and the people you work with.

Some people just need what I call a listening ear, a shoulder to lean on, someone to bounce an idea off of. Some people are like me and they have what I call go to people. I go to one buddy for car questions, I go to another person for financial questions, I go to my sister on educational issues, and you can put that into a Power of Attorney, or a support plan or Supported Decision Making agreement depending on your State. You can do that and write it up and say, I will work with you to do this thing in this way. And some people like it even more specific kind, called a Micro Board or a Circle of Support. I cant see everyone on this call but I got an email from an old of mine named Kish, who piloted Micro Boards and Circles of Support. She said she'd be on today. So hi Kish, I hope you are doing well. But they piloted the idea of a circle of support. Think of a personal board of directors, people you meet with real or virtually, relatively regularly, and you talk to them. Bounce ideas off of them, and you are hoping to spur debate, getting advice and discussions so I can understand from them what my options are and choose the best one for me, and all of these are Supported Decision Making because they all involve me going to you for support, you providing it and me making the decision.

In fact I always say there are three commandments of Supported Decision Making. If we can commit to these three things, we can all be advocates for Supported Decision Making, we can all empower people to use it to have their best possible lives.

Let me tell you, spoiler alert, they are easy. And all of them are easier than next.

Number one, we all agree collectively that everywhere has the right to make choices to the maximum of their abilities. That is easy. That is the Declaration of Independence, isn't it? We hold those truths to be self evident, that we all have the right to liberty of life, liberty and the choice of happiness. We have the right to make choices.

Number two, I can go to you for help, I can ask you for advice, I can ask you for help making a decision without you saying you must not be able to make decisions, therefore you should lose your right. That is easy, because we do that every day. We get advice, we get assistance, we have conversations with people we care about every day.

And third, and last, there are as many ways to give and get support as there are people. The first thing you try may not work. You ever have to go to plan B, C, D, E, F, G? I often go to plan QQQ, because the first thing you try to support someone might not work, it might not be the best thing for them. Keep trying. Try another way. Talk, examine, explore, because something might work, or nothing might work. If nothing works guardianship is probably appropriate, but why rush?

So, here are some guidelines, some thoughts on you you can explore this. Remember there is no way way to do this.

But this is some ways I have worked with people across the country on figuring out how to use Supported Decision Making and put it into action. So, the first thing you need to do is figure out where the person wants help. So the first thing you need to do is talk to the person. Where does this person need help, where does this person want help, what kind of help has worked for this person? There is a great tool, there is link on the screen, or find it by Google. It is called the Missouri Spotlight Tool. What the Missouri Spotlight Tool does is it looks at common, everyday decisions. Working with the doctor, taking medication, getting to work, managing transportation, managing relationships. It asks the question: Is this something that a person can do on their own?

If so, that is a green light. Go ahead and do it. Is this a thing the person needs help to do? A yellow light. Explore it. And is this something a person simply cannot do? A red light.

So, what I do is I look at the yellows and reds. I do it with them and a couple people in their lives to triangulate where the yellows and reds are, because that tells us where the help is needed. Once you understand where help is needed, the next question is, what kind of help is needed?

Here is a spoiler alert too, I guarantee just about everyone has used Supported Decision Making for something. At some point, someone has gone to someone else for advice about something. Something as simple as what to wear that day, to as complex as where to work. But you talked to them about it. And there is a resource called the Supported Decision Making Brainstorming Guide, which is designed to help people explore where they may have used Supported Decision Making before. What kind of decisions have you made? What worked well, what doesn't, what might work well. You know what great example of Supported Decision Making is?

Have you ever been to the emergency room? If you go to the emergency room, you will see on the wall pictures of faces that are designed to help you point to how you feel. They go from smiling to in great pain To indicate your level of distress. That is an example of Supported Decision Making because it allows people to communicate when they might be in too much distress to do so.

Maybe a person likes to communicate pictorially. Maybe they like to have things written out for them. Maybe they like to have people explain things orally. Maybe they like extra time to think, that is the point of the Brainstorming Guide, is exploring things and exploring options the way they have been done before. Third, once you know a person wants help in a certain place and the kind of help they want, the next thing to know is who. Who can help you? Who is in that person's life? Who has worked with that person before? Who could work with that person? Are there professional agencies? Things like vocational rehabilitation, which we are going to talk about in our next webinar in a couple of weeks. Special Education, Centers for Independent Living, Medicaid Waivers. Professionals who can help.

Are there family members, friends and others that can help? Who could provide that assistance?

Once you have that, once you know where a person needs help, what kind of help they want and who can provide it, put it all together. Make a plan. One of my favorite resources is called the Setting the Wheels in Motion Guide. What the setting the wheels in motion guide did, it was written by a friend of mine, a mom and an advocate by the way, who has three children with what we used to call severe and profound disabilities. And what she does in the entire first part is she talks about her supported decision making journey with them. How she put together teams and how she worked with them.

But the entire second part that I love, is worksheets. Ways to guide you through a plan. Think about who can help, how they can help, where they can help and what kind of help you want. So at the end of the worksheets then you have a plan.

You have a roster of people. You have work being done, you have opportunities, so that plan is something you can put in motion.  And the last thing I recommend is put it in writing.

Depending upon what State you are in, some States have laws recognizing Supported Decision Making and some require that there be Supported decision making agreements in writing. If you are in one of those states, absolutely do put it in writing. If you are not, I like putting things in writing anyway. A power of attorney is a great way to support decision making. But even if not that, its a great way just to have stuff. Think about it, people like stuff. Professionals, doctors, lawyers, agents and others like stuff. They like being able to say this is how I make decisions. Here is my plan, and therefore Jonathan will be supporting me, you need to talk to Jonathan, too, as much as you do me. There are great examples of written plans at the national resource center for supported Supported Decision Making, supporteddecisionmaking.org.

Or you could do it as easily for example as making a roster. I worked with a young woman in California, the first person in California to get out of a guardianship because she used Supported Decision Making, and our Supported Decision Making plan was just a roster. It just said who was on Maria's team, and what they did. Jonathan Martinis assisted with legal issues. An aunt works with relationship issues. So, we could show there was a working, functioning plan in place. I once worked with someone who came in to me, this was in Virginia.

She came into my office, after we worked with her on Supported Decision Making and she gave me a hand written chart, where she said this: This says who I want to help me, this says when I want them to help me. This says how I want them to help me. That is it.

I said, my God, it is it. Its as simple as that. That's how we make decisions. We figure out what we need to do, who can help us do it and how they'll help us. When we do that, we have supported decision making. The reason that is important, why is spent the first 20 minutes of this presentation talking about self determination being the key to quality of life for people with disabilities is this, the studies are coming in. I'm part of a bunch of them. That are showing that when people use Supported Decision Making, they have more self determination. And pardon me for being repetitive, but that is not rocket science either. If I am making my own decision with assistance from you, of course I have more control over my life than if you were making the decisions for me.

What we know is that when I have more control over my life, my life is better, including I am more likely to work, make more money and be self employed. Research has shown that time and again.

In Virginia we did a pilot project working with young adults. We what we found was that those using Supported Decision Making, they said they were more independent, more confident, and they felt better about how they made decisions. Their supporters said they made objectively better decisions. Even in the middle of the pandemic, they were saying they were doing more things, working more ways, and being more active. Its not rocket science, they were more self determined. They had more opportunities, and opportunities to use Supported Decision Making are all around us. If you think about it, if you have been involved in special education, gone to an IEP meeting, you know the Gold Standard is what is called the student led IEP. As the student gets older, the student plays a lead role on the team. The student works with the team members, his supporters. Her supporters.

Friends, the administrator, the teacher, the regular ed teacher, etc. etc. etc. And they work together to help create the IEP.

So that by the time the student is 18 the hope is the student is really playing a lead role on the team and can sign off on the IEP. Doesn't that sound like Supported Decision Making? The team and the person work together to support and the person decides. Any of you that have worked in Vocational Rehabilitation, the informed choice process is all about the counselor working with the person so the person understands his or her options. The counselor provides information about services, supports, jobs and the opportunities to get the training you need so the person can then decide what their job goal is and what they need to get there. Doesn't that sound like Supported Decision Making? If you have ever worked in Medicaid, Person Centered Planning is all about a team led by a Case Manager working with a person to help the person understand where they are now and where they want to be. Who they want in their lives now and and who they want in their lives later. The things they want to do now and later. Their goals, objectives, supports and services. Doesn't that sound like Supported Decision Making?

Even end of life planning, things like the conversation and what's called five wishes. They are an Iterative Conversational Guide designed to help people say what they want when they reach the end of their journey. Supported Decision Making. All of these are giving people power in their lives. Giving people opportunities in their lives, and what we know is that when they have more opportunities, when they have more control, their lives are simply better. I know some of you are probably thinking this what about safety? I call it the elephant in the room. Someone always asks me, well Jonathan if we do Supported Decision Making and not guardianship, are you sure my son, daughter, family and friends, whoever will not be taken advantage of, that they will be safe? I always say, no, of course not. In fact, the opposite may be true. I'm sure that right now, someone with or without a disability is being led astray by someone they trust. But is that really the standard we should be applying? Because if you are only allowed to make decisions, if you only make good decisions and you only have the best possible friends then, my God, I can never play poker with my friends because they get me to do all kinds of ridiculous things. We cannot condition our lives and decisions on what I call the Spock Standard. You only make good and logical decisions.

Because if that is the standard, look in the mirror. I sure hope you don't drink beer, I hope you don't eat cookies, lie in the sun. I hope you don't blow off work sometimes and take a mental health day. Because those are not logical decisions, they go against your best interest. Except they dont. Those are the things that make us who we are, those little quote unquote mistakes shape us, define us and help us to be the self determined people we are. By the way, there has never been a study that has found that people are inherently safe under guardianship. In fact, as I told you, there are horrific stories of guardianship abuse. It doesn't mean it is bad, but it means some people are bad and people are going to be bad. But what I said is we can empower People with Disabilities to recognize the potential abuse. Just like Dr. Khemka found. So, if you are giving me a choice between Supported Decision Making and guardianship, and say there is a chance of being hurt in both of those, man, the one I am trying first is the one correlated with self determination because it is directly correlated with enhanced safety. Why wouldn't we try that first?

If we do respect and protect choice, amazing things can happen. Ten years ago I had the incredible good fortune to work with a young woman named Jenny Hatch, who was the first person to win her right to make decisions instead of being put in guardianship using supported decision making.

The first person who went to trial, who walked into a tiny courtroom in a tiny town called Newport News, Virginia, and won her rights back even though she lost them a year before because someone decided a person with Down Syndrome can't make their own decisions. She showed she could.

There are people across the country. This is Ryan King. Ryan was the first person in Washington, DC. He had been in guardianship for 15 years. His parents never wanted to be his guardian. In fact, they told the school we dont want to be his guardians.

The school said if you want him to get services, you have to become his guardian. So what's a parent to do? They became guardians.

About 10 years later, they said this is dumb. Ryan can make his own decisions and we may predecease him. And by the way that is a smart comment because this is the first generation of people with disabilities that is statistically likely to outlive their parents. And they didn't want a stranger over Ryan. So they said, couldn't we do a power of attorney? Couldn't we do a plan? and you know what the judge said? If you don't want to be his guardian, we will find someone else.

So what's a parent to do? They stayed his guardian. A few years later Jenny happened, and made a lot of news, and they said this is what we do. So they tracked me down. So we spent the better part of a year creating a plan for Ryan.

And went right back to that judge, that Ryan had a plan in place. He was going to work with his family, he was gonna do this, he was gonna have systems set up to keep himself safe and self-determined. What I remember is after that trial, we had a Power of Attorney all set up and said, judge, if you get rid of the guardianship, he will sign this right now.

The judge looked at Ryan and he said, Ryan, your attorney says you will sign this if I get rid of your guardianship. Ryan said, yes, sir, I will. Then he smiled and the judge said, you can sign it if you want. That is your decision, and he ended the guardianship. That is Ryan signing the Power of Attorney with his mom next to him. His mom is a primary supporter and Ryan and his mom have testified before Congress, they have lectured Nationally and they have written articles all about what his mom calls Ryan's Journey of Supported Decision Making. This is Tonya, a person who had a brain injury. When Tanya had her brain injury she went into a coma, and her mother did the right thing. Her mother became her guardian, but as Tanya began to get her faculties back, she wanted her rights back, And her mom pushed back because her mom wanted to protect her. They went to court and the judge from Ryan's case called me in and said, they are depleting all of their money. This sounds like a possible Supported Decision Making case.

So, I worked with this family for about a day and discovered they wanted the same thing. Tanya wanted her rights back but wanted her mom to be there to help when she needed it.

The mom wanted Tanya to be as independent as possible but wanted to be able to step in if Tanya needed it. And just like that we created a Power of Attorney and now Tanya lives and works independently and her mom can help her when she needs it. These are things that happen across the country.

Day after day, someone is freed of guardianship or avoids guardianship because of Supported Decision Making. I told you Jenny Hatch's case was 10 years ago.

In just those ten years, 26 United States States and the District of Columbia changed their laws to recognize Supported Decision Making. More than half the country now has a law formally recognizing people's right to use Supported Decision Making, and I have been in court in several states that don't have laws and we have won the people's right to use Supported Decision Making. Why? One, because they can. And, two, we can prove it can make people's lives better.

That is the message I want the take to you.  If you want to make people's lives better, If you want to help people more likely to be employed, if you want to help people be more independent, if you want to help people be living, working and loving independently, then the place we have to start is respecting, protecting, acknowledging people's right to make choices. That we all have that right.

And we have to realize that I know it is different. I know that we are doing different things when we do that. You are probably thinking the same thing I hear all the time. Well, we don't do it that way. I get the finger wag - you are asking us to change the way we always do things. I get that lot this State agencies and litigation. We can't do that because we have always done it this way. And my answer is this. This is what I want you to think about this.

Hasn't every great advance in human and Civil Rights begun by changing the way things have always been?

I live in Virginia and I am talking to you today from Florida. Where I am sitting right now, in 1863, some people thought it was okay to own other people. We changed that.

In 1918, half the population, women, were not allowed to vote. That was changed. In 1963, it with us legal to keep people from using bathrooms or sitting at lunch counters because of the color of their skin. And we changed that. And in 1989 People with Disabilities were not considered in a legal sense to be people. We changed it. So, to say we have always done guardianship the same way since Justinian is to say we shouldn't grow, is to say that we shouldn't do things in new ways and that we shouldn't empower people. We can do better.

I know it is hard. I know it can be hard to change the way things are always done, and I know history pushes back. If you are empowering people to make decisions, guess what, some will make bad ones, people are going to make mistakes, date the wrong people,  buy the wrong things.

They are going to sign things they shouldn't sign. My God, I do that at least once a week. But you have to realize it is supposed to be hard. Being a human is hard. It is not easy. If you are a professional in this field did you get into this field because it is easy? You sure as hell didn't get into it for the money, you got into it to make people's lives better. If you know self determination makes people's lives better, than that's what we believe in and that is what we must do. And its not supposed to be easy.

 There is a quote on the screen from my favorite author and he says this. We were not promised that it would be easy. We weren't promised ease. The purpose of life is not ease. The purpose of life is to choose and to act upon the choice. When we do that. When we respect choice and we empower choice. When we give people the right to make choices. Then weren't not judged by one mistake.

Because if we were judged by one mistake, none of us would have rights. No, what we are judged by three things. Our daring, our effort and our resolve. That is what it takes you have to be bold, try new things, You have got to work hard and you have to get up when you fall down, because you are gonna get knocked down. People with Disabilities get knocked down every day.

And you know that well. And they get up. And you have to be willing to bang your head against the wall, because sometimes that is the only way to knock it down and let the light in. And if we do that we change the world. I have been talking at you for an hour.

Let me finish with a cliche. We can change the world. We change it one person at a time. I will tell you what I mean by that. Jenny Hatch took a year of trial and six days and won her rights back. Ryan King took a year in preparation and one day in court. Other cases go to court on an agreement. Most Supported Decision Making never even goes to court. Why? We know it works.

So, when we empower one person, what we are doing is empowering everyone that comes after that. Remember what we did for Jonathan, why don't we try that for Andrea? We can do something great for someone. Remember when we tried something new? We knew it worked, why don't we try it again. That is how the world changes.

One person making one decision at a time. Let me tell you, the other reason we should be doing this is because the services and supports facing People with Disabilities end. School ends, Special Education ends, work ends, Vocational Rehabilitation ends, Medicaid Waivers may end, Social Security may end, what is left at the end of the day is the person. Not a Person with a Disability, but the person. And what we are doing then is empowering people. Not People with Disabilities using Supported Decision Making, but people making decisions and getting what they need to live their best lives. The last thing I am going to say is this. If you have bought into what I have told you for the last hour, I am happy to answer questions about it the rest of time, but if you have bought into this, then we can work together to change the way things have always been, to empower people to have their best life, and to change the world one person and one decision, one at a time. If you haven't bought in, I just hope you die suddenly. And that is not a joke. My fondest wish for you is if you don't believe in Supported Decision Making, I hope you die suddenly. You know why? Because if you are not lucky enough to die suddenly, guess what you are going to be one day? You are going to be old. You are going to be infirm. You are going to be disabled, you are going to be in the system. What kind of system do you want to be in? A system that empowers you, that respects your rights and helps you builds your abilities, Or do you want to be in one that's 1,500 years since Justinian, that said, you need help doing something, we are not gonna let you do anything.

So, I think I know the answer. So, for yourselves, for the people you care about. For the rights you believe in and the people you want to support, we can use Supported Decision Making to make their lives better and change the world.

It has been my pleasure to talk to you today. That if my email address on your screen. And I'm happy to answer any questions, but I also recognize the questions come later.

If you think of something you would have liked to have asked, you can email me right there and we can talk, but right now, let's take the time to talk. What kind of questions can I answer?

>> NIKKI POWIS: I was talking away but muted. Thank you Jonathan, so much. You mentioned it a couple of times, but it bears reminding ourselves that yes, as we age we too will have more disabilities.

So, let me see. I have a question here. Can you provide suggestions for financial protection while maintaining autonomy.

>> JOHNATHAN MARTINIS: Absolutely. One of my favorites is the Power of Attorney. The number two reason I hear for guardianship after safety is financial management, and that is an absolutely real and appropriate concern. I talk to people about Powers of Attorney. You can use those. And what I like about Powers of Attorney is they are voluntary. With a POA, I can give you the right to make national decisions for me, but we can also agree how we are going to do it.

I worked with a young man with autism once and his mom was primarily afraid that he would be swindled, that he didn't have a good head for finances and is kid was pretty self-aware and said, yeah, I think so.

So we worked to do a Power of Attorney that essentially said this. For x dollars a month, give an allowance, go nuts, spend money, learn how to make decisions and make mistakes. Anything over that mom had to sign off on.

But before mom said yes or no, they had to have a conversation. Because, the kid may have been right and if so, he advocates for himself and mom signs off.

The kid might be wrong, and if he's wrong, mom can work with him on why and how to do it better. Like, if the kid wants to buy a car, instead of saying no, we are not doing that, mom can say a car costs this much, and you have to have this much money for insurance and maintenance. So, why don't we make a budget. You get a job, you put away this much per month and there will be a time you can do it.

So, just like that, instead of a yes or no question, and guardianship is largely a yes or no question, we can create a safeguard. There are lots of other tools. I am a big fan of ABLE accounts. They can help people to earn, work and save money without losing their benefits. But what they can also do, because the person that holds the account is charged to manage the account, decide how much to put in, how much to take out and when, that is a great opportunity for Supported Decision Making, to give a person access to maybe look at records and balance budgets and talk together, so you might be able to create a Decision Making process if that way. Supported Decision Making works great as we will talk about in a couple weeks with Vocational Rehabilitation, helping people learn to work, and manage their benefits and manage their money. There are lots of ways. I am happy to talk about it offline because it goes well beyond the time we have, but SDM is tailor made for financial decisions.

>> NIKKI POWIS: Theresa, has raised their hand, did you want to come off mute and ask your question? I see you have your hand raised. Or if you need to be using ASL, you can turn your camera on. Theresa, maybe you need to unmute? Okay. I am not sure.

Also a few people have come on camera. I don't know if you are wanting to ask a question. Ronald, Sarah, did you have a question? Is that why you are on camera? No. Okay. All right. Just checking.

Let's see. Who is the author of the Brainstorming Guide? Is one question.

>> JOHNATHAN MARTINIS: That was written jointly between the American Civil Liberties Union and the Equality Trust for Individuals with Disabilities, who was the lead partner in the national resource center for Supported Decision Making. I wrote it with people from the ACLU. Someone asked me to read out my email address. I am happy to, ma'am. It is: Jgmartinisllc@gmail.com. jgmartinis@gmail.com.

>> NIKKI POWIS: Ok we have another one here. If I feel like the support brokers in my child's life need help in understand SDM, how do I advocate for schools and government agencies to get the much-needed training?

Why we need to build the capacity. Yes. There is more, but I think that was the main question.

>> JOHNATHAN MARTINIS: There are lots of good resources out there you can share. And, again, please forgive me for sounding like I am patting myself on the back, but there is lots of good stuff that I have been a part of writing. The Missouri Developmental Disabilities Council, and you can Google Missouri DD Council has a series of short, easy to understand brochures, that are designed to give background information on Supported Decision Making and applications of it. They are all about 5 to 7 pages long.

Meaning they are long enough to give good information and not long enough to get boring, and have other resources to go to, so I strongly recommend those.

There is one on essentially what we talked about today. There is another on using Supported Decision Making in Special Education. Another one on using Vocational Rehabilitation, another one in using healthcare, so there are opportunities using Supported Decision Making to help people, and help organizations learn about and build systems.

>> NIKKI POWIS: Ok. Umm. How might the Supported Decision Making apply for entrepreneurs, wannabes like me with Disabilities, and yeah, that is basically the question.

>> JOHNATHAN MARTINIS: First, you are not a wannabe, are already an entrepreneur. Anybody that makes the decision they want to do this, is this.

Understand, you have already taken the most important first step, deciding you want to do it. With regard to Supported Decision Making, there are tons of ways it can help you. One of the great things you can do, again, talking about this in a couple weeks, is working with your State's Vocational Rehabilitation System to learn about and access supports and service to help you to be self employed, and to help you be an entrepreneur. You use Supported Decision Making throughout that process. They call it informed choice, working with your counselor to understand things.

If you have a Medicaid Waiver where you work with a Center for Independent Living, it is an opportunity to get support to understand your options and make decisions.

What I want you to do, and I know one of the reasons why I don't I have become less enamored of the phrase Supported Decision Making, is it sounds like a program or project. But in actuality, it is just life, its just getting information and making decisions.

So, everyone you work with has an opportunity to use Supported Decision Making simply by saying I want your help. I want you to help me understand and do the things I need to do. It is an absolute paradigm shift from the way it has always been done, but it is the right thing to do, and the studies back that up. So, here is my advice. You go to the people you know and work with and say, this is how I want to do things. I would like you, potential supporter, to help me. I would like you, agency, bank, lawyer, whoever, to work with me with my supporter. You are setting up a system that is really no different from the systems everyone else has. The only difference is you are a person with disabilities and society hasn't thought you can do it.

You can show them that people can.

>> NIKKI POWIS: This speaks a little bit to answering the next question. But, what do you suggest for people with unsupportive families and few friends?

>> JOHNATHAN MARTINIS: Well, that is what the American Bar Association called people unbefriended. It is a very sad situation. Part of that involves working with people you can work with. Every community has what is called a Center for Independent Living that you can reach out to to request assistance in all kinds of things. You can try to build your circle, going to organizations that work with People with Disabilities and saying that I want to take these next steps, and I'm looking for people to help me. That is how you do it. You build your circle.

If people don't want to be in your circle, then you either help them understand that they should be, or you simply say, okay, I am going to leave you behind. I will be back when we can still be family and friends, I can still love you, but I am going to move ahead and manage my own life this way.

>> NIKKI POWIS: A couple people put their information in the Chat. Someone from the Iowa Vocational Rehabilitation put their email in there. If you're in Iowa. You did already say out loud your email, didn't you, Jonathan.

>> JOHNATHAN MARTINIS: I did, and I put it in the Chat Box. I will put it in again, because I know a lot of people have been talking. That is great. I love that we are having conversation. That is the other advice I can give you. Find people to have conversations with. Find your people. That is the great thing that the internet gives us, the opportunity to have conversations like this. Exchange information.

People on this call have probably experienced what you are going through right now. It is a chance to network people who have done it. It is a chance to build your group.

So, take opportunities to build your circle wherever you can. This is a great opportunity. Please reach out to me or some of the other folks.

>> NIKKI POWIS: Just in case we missed it, somebody needed it verbally J G M A R T I N I S, so, that is jgmartinisllc@gmail.com. Let me know if you still need it again. So, balancing Supported Decision Making versus guardianship for medical, especially in life, death possible situations due to expected surgical, etc. What resources do you recommend?

>> JOHNATHAN MARTINIS: Power of Attorney with advanced directives, absolutely. Again, there is a real difference between a Power of Attorney, Advanced Directive and guardianship. In Guardianship, you have the right to tell me what to do.

In a POA or Advanced Directives, we work together on what to do. I have done many advanced directives around healthcare where we say, maybe ultimately, you do get to decide what to do, but here is how we will do it. You can ask me first. I will give you certain decisions I will never agree with. I will never consent to electroconvulsive therapy, I will never consent to taking Haldol. And with those parameters how we can create our decision making method, in an emergency you have the power to make that decision, but we go through a specific process on how to make it. In the case of Tanya, the person I told you about, we wrote a very detailed Power of Attorney that basically wrote out certain decisions. We said mom, the POA, her job was to make the decision that Tanya would have made, not necessarily the one mom thought was the right one. So, we had a whole bunch of decisions about that. We can create a cooperative team even if you are giving someone else power to make decisions at the end of the day.

>> NIKKI POWIS: We're gonna run out of time. I want to make sure everybody knows we will be sending out the PowerPoints, and we also have the guide that Jonathan wrote. I am not sure if we put a link to that in the Chat, but if not, we can do that now. We will also be emailing it out to everybody that is on the call.

And, Jonathan has alluded to the follow up. Next you know, the next episode, next in the series, which is January 31. It is the second part. And we will actually for that be having a panel of a couple of families who have used Supported Decision Making, who have found that successful, so you will be able to hear directly from them. We do have one more question. What would you say to a young person who doesn't want to have a guardian, but is being told he or she needs to, because that is the way it is.

>> JOHNATHAN MARTINIS: I would say, what do you think when you hear that? Do you think that you can make your own decisions? Are there ways in your life you can have that done? Are there ways you can work with other people to have the best possible life in your heart of hearts. In your brain, do you know you are capable of directing your own life? If the answer to those questions is yes, then when someone tells you that you have to have a guardian or need to, especially because that is way it has always been, frankly, I would tell them to go to hell. Simple as that.

>> NIKKI POWIS: Very good!

>> JOHNATHAN MARTINIS: By the way, I had much stronger language in mind, but since this is being recorded, I am more colloquial. But, really, to whoever said that, it is your life. You have the opportunity to build that life.

That is what self determination is and to have someone else based on 1,500 years of outdated thinking, telling you that you have no choice. I would just say go to hell. You can do better. And this world will be better when you do better.

Thank you so much. It has been my honor to be here today and I am looking toward to seeing you all in a couple of weeks.

>> NIKKI POWIS: You are getting a lot of praise in the Chat, and appreciation for what you have been talking about today.

We also did have someone asking for support from small business. Lexi, can you put our link to the NDI supports, for small business, the National Disability Institute does have a small business website. Lexi put it in there just now. We have a multitude of supports and services if you are an entrepreneur and you are looking for small business.

And Ruth just put her email in the Chat. Which is RChavez@ndi-inc.org.  She is actually our navigator and person who does one on one business counseling. We will send all that information out to you, so you will have it in writing in an email. Everybody is saying great presentation Jonathan. You have got a link here to register for upcoming events. We as have streaming television channel geared to individuals with entrepreneur and small business owner opportunities.

Well, we are about at the end of our time. I don't see any other questions, I am trying to scroll and see if there are any other questions. I don't see any. We have about 2 minutes left. Any parting words, Jonathan, before we say good bye to everyone.

>> Self determination is the key to life for People with Disabilities. And without disabilities. Just by being here today, you made a commitment for yourself and the people in your life.

If you heard things that inspired you today, if you learned things that can help you in your life today, the best thing you can do is, one, do them. And, two, tell people about them. You are now all Ambassadors. Every single person that believes something I said was correct now has a moral obligation to spread that word, because there are people out there that haven't heard of it. And Supported Decision Making is natural. It is something people can do.

They don't need to be on a Webinar like this. What they need Ambassadors and advocates to tell them, to empower them. Each and every one of you is now one of those. That is how we change the world, and I will be honored to do it with you. Thank you so much.

>> NIKKI POWIS: Thank you for joining, everyone, and look for the emails to get the information, transcript, and, thanks again, Jonathan.

>> JOHNATHAN MARTINIS: Have a great night.

(Recording stopped)

 (Session was concluded at 5:29 p.m. ET)

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