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Good evening everyone. My name is Kate Bowden I'm one of the attorneys and we're so pleased to welcome back Jonathan Martinis tonight for your next workshop

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In a series of workshops he's the senior director for the university and he represented Margaret Jenny hatch the first trial to hold

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That the person has the right the use supported decision making to make her own life choices

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Instead of being subjective to a permanent full guardianship. Jonathan has led projects across the country about supported decision making.

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He has educated and trained then of thousands of people with disabilities and their families and professionals about support Decision-Making theory and practice. And he has written and cowritten

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On thirty publications on this topic. I must say I have been wowed by his workshops

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And I'm so excited to hear what he has to share with us tonight. And I will turn it over to you Jonathan and take it away.

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JONATHAN MARTINS: Thank you so much Kate before we begin I want to apologize for the poor quality of our video tonight.

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It's my fault or more truthfully mother natures fault. I'm speaking to you from a hotel room. If you saw the news. You saw a 50 mile back up that closed internet 95 and my house is in the middle

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And we've been without power and heat and today we gave up and came to a hotel

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So the poor lighting is part of the deal and we'll muddle through today.

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Today we're going to talk about what I think is the most important part Decision-Making the ways we could use supported Decision-Making to make people's lives better.

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Ways that I call healthcare and life planning. Those day-to-day things that we have to do to take care of ourselves,

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To take care of our health, to take care of our financials.

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And the way that supportive Decision-Making can help trace a line all through life

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To ensure that we have the best quality of life.

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So with that lets begin and I'm going to share my screen.

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I and we'll begin.

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And as always, we begin with what I call an article of faith.

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And the article of faith for this presentation comes directly from the Americans of disability acts.

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It say that is physical or mental disabilities in no way diminish a parents right to fully participate in all aspects of society.

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Note that phrase all aspects of society. It's shocking it took until 1990 to say that.

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All men are created equal it took until 1864 to say all men whatever their national origin are have equal right. It took 1919 for women to have equal rights to vote.

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It took until 1964 for all races, colors and gender to have equal rights but it wasn't until 1990, 214 years where people with disabilities

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Were qualified fully and equally as people

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That's where we are and that's what the law says.

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We now know that people with disabilities have full and equal rights all through society.

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And here's something else we know that self-determination, that people who have more self-determination, who make more choices

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Who make more decisions, who have more control over their lives have better lives.

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Those are the two articles of faith for this presentation.

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One, people with disabilities have equal rights to do everything that everyone else does.

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Two, people with disabilities who exercise more determination have better lives.

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They would be better able to fully and access all aspects of society.

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In fact we know from 40 years of studies that people with disabilities that have more self-determination

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Remember make more choices are more likely to work

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More likely to make more money, more likely to be more integrated in their community,

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More likely to be safer.

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The key to full and equal participation is having more self-determination.

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As we discovered a great way to get to self-determination is supportive Decision-Making.

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The definition on your screen that I told you I don't like it very much even though I wrote it saying with people with disabilities

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Work with family and friends and professionals that help them understand the choices they face so they can make their own decisions

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Which means supportive Decision-Making is getting help from when you need it from people you trust to do what you need to do.

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That's it. Supportive decision making is getting what you need to do what you have to do.

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Something with people without disabilities do everyday without thinking about it.

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I gave a presentation earlier today from Nebraska and I heard a mother and daughter talked about they used it

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They said we been doing it for years and never heard the phrase supported decision making.

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Right. Who calls it supportive decision making.

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It's just life. We all get help to make decisions everyday of

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That is what supportive decision making is.

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Here is what supportive decision making can do.

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We're seeing the research showing that people that get support who make decisions their own decisions with support have more self-determination.

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I said time and time again it's not rocket science.

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If I'm making my own decisions of course I am

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Working to get a publication out on it as soon as I can

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But what we did is work with ten young adults and power talked to them

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And what we found after a year worth of this project and interviews with them and their supporters and interview of qualitative data that across the board all of the ones that

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Use supportive decision making were better at making decisions and made objectively better decisions

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Even in the middle of the pandemic the majority said they were doing more in the community

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Being with more people and all in all having a better quality of life.

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Maybe that's why we're seeing time and again powerful entities are endorsing supported Decision-Making.

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U.S. department of health and human services funded the decision making and I'm one of the directors of.

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The American Bar Association as strongly induced the state laws the

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National guardianship association said we should say SDM

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And like the arc the national asilence of mental illness AARP have come out strongly in favor of SDM.

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And yet especially when we're talking about quality of life even with that and all of that data

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Particularly when it comes to healthcare, what we're seeing is that people with disabilities are not

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Having full and equal access.

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In fact what we've seen the U.S. surgeon general found even when they have more medicalal conditions

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Still have either getting over treated or under treated or getting poorly diagnosed or treated.

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That could be because in study asking what was the first prompt for guardianship, what was the first thought

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The number three identified source was doctors.

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That doctors are making assumptions that people cannot manage their own healthcare



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Or should not manage their own healthcare leading to guardianship

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Leading to loss of self-determination and loss of rights.

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So what we have found is that

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And what we hear time and again from doctors, I have heard this many times and what I heard often and heard back from parents

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Is the reason they recommend guardianship or the reason they feel people with disabilities can't be a leading part of their healthcare

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Is because they cannot engage in what's called inform choice quote unquote.

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So when I hear I went back and did research and found the professional association for doctors and they identified

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As the heart of the doctor, patient relationship. The most important part.

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And the way they describe inform consent is this, information exchange.

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I tell my doctor what my problems are, how I'm feeling

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The key part ST doctor is supposed to give the patient information, give the patient information about a diagnoses.

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Say this is what I think you have, this is what I think you should do.

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The patient is then supposed to receive that information,

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Understand it,

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And then make a choice on what to do.

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Whether to follow that advice.

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Whether to not follow that advice,

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Whether to ask more questions and communicate that choice to the doctor.

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It's all about information exchange.

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I'm telling the doctor how I'm feeling and the doctor is telling me what the diagnose is and I say okay doctor

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I do what you recommend or tell her I won't do or think to myself, I need more information from her about what she recommended.

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It's all information, from me to you, from you to me.

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And then choice by me. That is informed choice.

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What we know and what we should expect is at every level of that exchange we can use supported decision making.

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We could use support.

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I could work with a supporter to help me explain my symptoms to my doctor.

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I could work with a supporter who can explain to me what the doctor is saying to me.

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Or to help me ask the doctor to explain it in more plain language.

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The key part here is we have to realize and doctors have to realize that informed consent is not a black or white issue.

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An ability to make decisions is on a continuum like every other ability.

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Think about it this way when a doctor tells me, when I go to the doctor I say please I feel terrible, I have the flu. Help me feel better.

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The doctor says okay take one of these pills for 6 days, it's a classic Z pack, I love it and always work for me.

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I have no idea what is in that Z pack.

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I won't read the tiny letters in the packet that comes. So what I do is I trust my doctor.

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I understand my doctor thinks I have the flu or has strep throat and I say yes I will.

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But here's the thing, I'm not the doctor, I have no knowledge of really what's in that Z pack.

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I have no knowledge of how it works.

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So consent, informed consent doesn't require me to know everything.

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If it did I would have to be a Dr.

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It requires me to receive the information and understand it with the support of the doctor.

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So the doctor recommends Z pack, the doctor tells me how long to take it and the doctor says this is what it will do.

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I may not know any of that.

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But I can trust the advice of my doctor. As a result I could give informed choice.

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The information that came from my doctor, helped me get what I needed to make that choice.

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In other words that means that using supported decision making gives us a flexible way to incorporate that informed choice process.

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Because there are many ways I can understand,

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There are many ways I could get information that I need

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And it can be on the spot. If I have a supporter there it will make communication more streamlined line

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It's going to improve communication.

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How many of us find it's helpful to have a third person in the room?

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I had my wife in the room with me when I gone to the doctor to make sure we have good open communication and understand everything that we need to understand.

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That is something that is helpful and it improved communication.

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And it increases the role of family and friends and professionals to lead to a better

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More important, more effective decision making process.

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That's what supported Decision-Making is. Part of the U.S. health and human services said it's different for everyone.

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I stress that the first time we talked.

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There's no one way to do supported Decision-Making. We all do it.

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We all need support and we all use that support in different ways.

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So I may do it best one on one with my doctor asking my doctor a bunch of questions.

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Can you explain that, can you explain this and put this in plain English.

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I may do better being nervous having someone come with me and helping the doctor what I'm saying. And maybe better for me to not make decisions on the spot

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And receive information from the doctor and take it home and discuss it and make a decision. As ACL says with supported decision making the possibilities are endless.

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We look for the thing that works for the person.

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If we do that we could enhance people's control over their life.

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Their self-determination involvement in their healthcare.

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Think about it people who would otherwise be assumed they can be informed choice and pushed in guardianship will now be able to work with supporters

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Understand their choices, make informed decisions and manage their healthcare.

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Doctors might otherwise recommend guardianship can now work directly with the person.

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And what we know from studies having better communication with patients leads to better outcomes and greater satisfaction in their job and less burn out

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So it's exactly what the doctors want and family members and friends and others who might otherwise be concerned about the person.

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Who might otherwise be thinking they need to seek guardianship can now become supporters.

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And be part of a working process to enhance that person's healthcare

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Which as we know is direct result of enhanced self-determination.

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So all of this results in a person having more control over their healthcare. More control over their life and more opportunities to make decisions and greater involvement in their healthcare

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And we could do it easily.

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I get it all the time from the doctors.

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We can't do that and have the third person in the room because of HIPAA. We all heard of HIPAA

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Where they say oh no we are required to keep things provide

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We could not have a third person in the room.

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I say that and I hear that from doctors I get confused.

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I tell them every time I come to the doctor, me, any time any of us goes to the doctors these days. We're giving a big long form to sign

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It might say private notice, notice of privacy policies but they all say the same thing.

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They are all based in HIPAA and what they say surround HIPAA. We can't share your information with anyone else.

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We are not allowed to share your information with anyone else.

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Expect someone you choose.

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There's always a line. There's someone I want you to share my information with, my other doctor and family members.

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So what is the difference between sharing information as permitted by a HIPAA form and supported decision making? There's no difference.

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Supported decision making is just sharing of information.

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It's sharing of information between doctors and patients. And doctors and supporters.

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So you could take that HIPAA form and they all give you a place to write in an in the name

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And you could write next to it for decision making purposes.

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Just like that you have given the doctor authorization to share information

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And engage in supportive decision making.

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If you don't want to use the doctor's form you could use your own. There are model at supported Decision-Making.org. They are all HIPAA compliant

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What we need is simply permission.

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A doctor is right when a doctor says they can't share information.

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They are absolutely right. So if a doctor says without permission, I can't share this information they are correct when it comes to HIPAA.

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But here's the thing about HIPAA the rights belong to the patient, not to the doctor.

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It means the doctor can't say I won't do this. What HIPAA says the doctor has to say I won't do this, unless you give me permission.

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HIPAA rights belong to me, not the doctor.

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So the doctor he or she cannot share my health information unless I give that doctor my permission.

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That is what HIPAA does. So HIPAA does protect your right to privacy.

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HIPAA does prevent doctors from sharing your information.

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But HIPAA also gives you the right to share your information and to tell the doctor

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To share your information. That's called waiving your HIPAA rights with regards to a particular person.

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I could say I waive my HIPAA rights for Kate Bowden because I want Kate Bowden to be my supporter.

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I want Kate to come to the doctor with me so I could understand the doctor better.

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And the doctor can understand me better.

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So even though doctor under HIPAA you can't share my information with Kate, I am waiving my HIPAA rights

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So you could share it specifically with Kate.

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So if we look at it that way, then that information sharing leads to supported decision making.

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I share my information with the doctor. Or I work with Kate to help me share information with the doctor.

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With permission I'm asking Kate there and asking to share the information and the doctor shares information with me.

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Here's what I think is going on.

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Kate is helping me understand that. And Kate and I want to talk this over what I want to do. And which medication I want to take whether I want to take any medication.

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Whether it's a big decision like surgery. By then make my decision and I'm able to communicate with Kate's assistance to the doctor.

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That's what supported decision making is. Helping me share information

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So you could go right to the doctor like I said and you could change that HIPAA release.

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You could write on that HIPAA release. I also authorize you to share information with Kate, to help me make decisions.

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Or we could simply write our own form and there's language on your screen, steal that language if you want.

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You could make an authorization to give the doctor permission to share my information with him or her.

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You could also create a different release, and again here's information on your screen.

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This is a very formal one where you could write this up and say to the doctor going forward.

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Instead of change it every r every time. We give the doctor one agreement and say that I authorize you and Kate to come with me and I want Kate

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To be just like me when it comes to my medical regards.

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Records.

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That means I can see the medical records and Kate can see the medical records.

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It specifically quotes HIPAA. I'm releasing you and giving you permission, I want you to share information with Kate so she can help me understand

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Make and communicate my own medical decisions. And we could do that even more formally. We could create a power of attorneys.

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They are great things.

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I always recommend people have power of attorney. They say what should happen if God forbid something happens.

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What they say is they build in supported decision making.

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So a power of attorney says God forbid something happens with me and I can't make decisions, I want someone else to make decisions for me.

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I want Kate, I want carry walker is something that I see on the screen or Bruce to make decisions for me if I can't do it.

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But we could include in that language that incorporates decision making.

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Yes I'm giving you power to make decisions for me, but

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To the maximum extent possible you have to give consideration to what I want.

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Even though it's your decision you have to check with me, and check with what I want

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And to if maximum extent possible do what I think is right.

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That's one way.

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For medical care we could do that more specifically.

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I know there's a lot of words but this comes from the power of attorney I did for healthcare.

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For this one the person we're working with had specific preferences.

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What we did is god for bid something happens to me, it was her mom in this case has the power to make decisions for me.



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But you're going to make a decision in the way I'm telling you now. So if one day I'm incapacitated you're going to use these decisions that I'm making as a guide

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It's a thing like I never agree to medications, what we said in making any decisions about my healthcare

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You have to check with me first, if I haven't given you specific instructions you have to check with me first

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And you're going to do what I want you to do.

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And if I'm unable to say what I want, if something horrible happened

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And I can't say what I want

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You have to make the decision I would have made. That you would think I would have made

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Even if it's not what you would have done.

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That's the essence of supported decision making right there.

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Where ahead of time you could make your preferences known. Right now if that day ever comes what I want you to do is make decisions consistent with this guide.

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I don't want this medication or treatment

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Even if I can't make my own decisions it gives me maximum ability to be involved in it.

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That works if a person isn't incapacitated.

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Because what if you know that you are able to make decisions now but still want help doing it.

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You could do a power of attorney or medical decisions I want you to do it for me.

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But then we could also say even if I'm able, while I'm able to make decisions I still want your help.

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I still want your help in making it.

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When my agent you does not have power to make my decisions

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When I'm still making my own decisions, I still want you to come to the doctor with me.

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I still want you to help me understand the situations I face and decisions I have to make.

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I still want you there so I'm able to make decisions to the maximum extent possible.

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I'm able to be the final decision maker with your support.

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That brings us to a point where we're in regardless of your condition at that time maximum control of our healthcare.

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In all of these, these are all using supported decision making one way or another to ensure that the person has

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Maximum decision making authority throughout his or her life.

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So I think that is a great opportunity for us to move forward in using supported Decision-Making to make people's lives better.

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Okay was there a question?

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You're on mute Kate. Kate Bowden can you hear me?

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We had a question about what do you do about if the doctor questions the person's capacity to even understand and use a power of attorney type document?

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JONATHAN MARTINS: I don't have a lot of patients for that. Here's the thing

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Every state law says this, every person is presumed to have capacity until they are found not to have capacity.

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So if I have a valid power of attorney that I present to my doctor

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And my doctor said I don't think you have the ability to sign that power of attorney.

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To me that doctor has two choices, go to court and seek guardianship or go to court to seek invalidate power of attorney.

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I do not believe the doctors should have the authority go behind the power of attorney without taking the steps -- in some states they are even penalties

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For ignoring a valid power of attorney.

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If they think it was gotten through abuse or exploitation go to protection and advocacy but do something don't just say no.

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KATE BOWDEN: I'm take it up a notch what about situations where the person

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Doesn't communicate with or understand language?

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JONATHAN MARTINS: That's a biggie to me because that assumes that communication is a solely a form of spoken language.

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There are a million ways to communicate. A million.

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I know Kate I'm speaking to you and you know this but in our world we have seen so much communication

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You know that study I talked about in Virginia of the ten people we worked with five are nonverbal.

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I just call it nontraditional communicators.

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They had other ways of communicating. Some spelling, some used signs.

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And what I have to do and my job is to find that person's language. Not to judge that person's language.

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On a personal note my uncle has cerebral Palsy. He couldn't speak

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My grandfather fought for him to be educated so he could use a letter board to spell.

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God for bid anybody that requested Bob's communication.

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You can't make decisions because you can't speak.

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There's a whole lot of people that have to say about that and we'll be if the front of that line.

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KATE BOWDEN: Okay thank you I'll pop back out.

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JONATHAN MARTINS: Okay the power of attorney give people the maximum opportunity to be involved in the decision making process.

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But that's not the only place we could use supported Decision-Making. Medicate waiver are tools to help people live and thrive in the community

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But to be part of the medicare waiver you have to be provided with person center planning.

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And I pull what you see on the screen directly from medicaid's guides and regulations

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They talk about person center planning is.

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Take a look at what it is supposed to do.

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It must address and long-term services and support in a manner that reflects individual preferences and goals.

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The guide goes on to describe how the person should have a person centered planning team made up not just of his or her providers

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But also of family members and friends and others who understand the person.

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So that the person is able to communicate.

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With support from his or her team, what is important to him, what is important for her.

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Where the person is now, and where the person wants to go, what the person wants to do and what the person wants to be.

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The idea is the team helps that person receive the information he or she needs to make those decisions

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To understand his or her options

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So that person can decide what kind of life the person wants.

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That is just supported Decision-Making is it.

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Is just one more example that I could get what I need to make decisions my by working with a team.

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It's a classic example look at all the things the person centered planning, a person on a medicaid waiver is supposed to have goals and preferences around community participation. Employment, income, and saving, and this is a tool, a critical pathway for independent and community integration.

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What do we know is the key self-determination. We get there with the person making the decisions

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We get there with the support of the team.



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There are many ways to get that support.

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I hope that many of you identify SxD working with the local center for independent living.

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If you're not I strongly recommend you find your local CIL there's a website where you could locate one closest to you.

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I think CIL are wonderful agency because the whole point is to be in the community and help people live independently in the community

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And help people have more equal opportunity and the whole mission is to help people have full and equal access

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To their communities and opportunities.

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And CILs do through through the support they provide.

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Here are some examples of what CIL can do.

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They can provide independ living skills training,

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Peer counseling, housing services and other services that will help people function in the community.

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So why shouldn't that include support?

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Why shouldn't that include Decision-Making support?

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Choosing how and where I want to live.

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Choosing the healthcare I want.

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And the beauty of it is the majority of CIL employees by law must be people with disabilities.

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So if you go to a CIL there's a good chance that people with disabilities can work with others that can provide support

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By using supported Decision-Making because they use it in their lives and because they have developed those circles of support

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Those teams around them to help them learn, identify the support they want, identify who they want the support from

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And put that support in place.

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Something else I want to talk about medical care.

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I think it's a new development. You may hear the phrase shared decision making.

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And it's important to talk about this. Because it's something increasingly coming online in the mental health realm.

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We have to understand choice.

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Now when I go to the doctor, remember we talked about going to the doctor, the key process is me understanding what the doctor recommends

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And me choosing whether or not I want to do it.

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I get to make a choice whether to follow the doctor choice or not.

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I have every right to not follow the advice.

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I have that right. It's a phrase for it.

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Doctors call it making a decision AMA or against medical advice. If I make a decision AMA it's my right

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I listened to the doctor and considered what the doctor said and I chose not to do it.

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Maybe I don't want to get surgery and I want to try a different medication and I wanted a second opinion and wasn't ready to jump in.

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So I have the right. Everyone has the right to make decisions a.m.

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AMA

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Recently there's been a push in regards to people with disability about AMA

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And remember there's nothing wrong with making decisions AMA

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Unless you are a minor where parents make decisions for you or under guardianship then you could make those decisions AMA just like everyone else.

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But recently

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We've seen a new phrase called shared DM sometimes called SDM and here's how it works.

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In shared decision making the person in the health care profession talks about the issue.

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Information is given, support is given so the professional can give his or her advice.

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The doctor can say this is what I think you should do and have this medication, or treatment or this course of action and then the doctor and the person

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Try to reach an agreement on the decision

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The person can decide what to do.

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Yes I do want to take that medication, no I don't.

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Yes I want that treatment, no I don't.

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But the only time the doctor will follow or honor that decision is if the doctor agrees with it.

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In other words let's say the doctor I recommend or let's say I have done an short inpatient stay because I have mental health crisis and I have found now to be stable.

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The doctor might say you may want to stay on a few weeks to get medication.

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I might say AMA I think I want to be discharged.

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Under shared decision making I won't be allowed to make that choice because the doctor didn't agree with it.

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The shared part people not under guardianship will lose the power to make decisions AMA because my decisions are only honored

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If the doctor agrees with it.

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Now I have to say even though I have concerned about share decision making and I guess you could guess what the concerns are

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That people with disabilities don't have equal rights in that decision

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There's nothing wrong if that's what you want to do.

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I had many people say I like shared decision making because it gives me an important check if I'm in a psychological crisis so there's nothing wrong or illegal about it.

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I want you to know it exist.

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You maybe offered SDM and know there's a difference between shared decision making and supported decision making.

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One size does not fit all.

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It may work well for you but ask questions about any healthcare that's part of supported decision making too.

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Let's talk about another kind of healthcare.

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This is particularly important for young children and young adults.

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How to get supported decision making through the medicate system.

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If you are under 21 or under 26 and receiving foster care these are the five most important letters you could imagine.

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Anyone under 21 getting medicaid or a parent of someone needs to know about this program.

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And it's called EPSDT. Early and periodic screening diagnoses and treatment.

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To tell you about it I have to tell you about medicaid a little bit and how it works.

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Okay. I'm sorry my slides slipped.

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I first have to tell you how medicaid works. It's a contract between the federal government and the state government.

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To Kate let's assume for a second I'm talking to Kate Bowden because she had the experience of being the moderator here. I'm going to be the federal government.

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Here's how it works, I as the federal government say to Kate who is Rhode Island do you want a whole lot of money.

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Million of dollars if you want that money you have to agree to be part of the medicaid system. Every state has agreed to be part of the medicaid system.

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Here I am the federal government I want to give Kate Rhode Island to become part of the medicaid system there's a whole bunch of things you have to do.

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There's a services and supports you have to provide.

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We're going to call it -- have you ever gone to a Chinese restaurant

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There's always a column A and a column B.

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Column A has a bunch of things you are going to have to do if you take this money.

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You have to do all of these things in column A.

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There are things like assisted supported Decision-Making.

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You don't have to take this money to be part of medicaid.

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If you do there's stuff you have to do in column B. These are things you don't have to do to be part of medicaid.

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I'm offering additional money to do them. You could not do them.

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These are classical things like dental care. So Kate you could have the second truck full of money or not.

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Here's the thing if you don't take the second truck you don't have to do column B.

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You're going to have to do column A regardless because you are part of the project but not column B unless you take the extra money.

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Many states don't take the extra money.

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There are many states that don't do things in column B. Here's the cool part.

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If you're on medicaid and under 21, and it doesn't matter how you're getting medicaid whether through the state plan, through a waiver

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Through an HMO plan as long as your on medicaid, and your under 21 you are already getting EPSDT.

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You don't have to apply for it and ask for it. You just get it if you are under 21.

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If you are under 21 you are automatically getting it. You get everything column A and B whether or not Rhode Island said we're not taking the extra money.

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If you are under 21 you get all the column B stuff. So anything, anyone can provide anywhere under medicaid you have a right to if you're under 21. Here's the simplest example I could give you. When I was with the Virginia protection and advocacy system.

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Virginia did not provide dental care under medicaid.

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Dental care is a column B issue.

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Virginia did not take the money.

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So the only dental care people with medicaid could get was their teeth pulled and there were hospitals and institutions full of people

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With disabilities who had no teeth because that was the only dental care they could get.

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Virginia did not have to provide dental care and didn't take the column B money.

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But Virginians under 21 got dental care because of EPSDT you get everything in column A and B.

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I had ton of cases where we got things that never would have been gotten for adult, equipment, bikes and once a jungle gym and had to do stretching exercises.

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And the doctor determined this was the best way to ensure the stretching exercises.

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There was specific diagnoses and specific prescription for specific exercises that can be done under this EPD

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So that's what you need to do about EPSDT I'm sorry for the long winded descriptions

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But it's 2 are greatest healthcare program for kids on medicaid.

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If a kid is under 21 they get anything, anyone can provide any where under medicaid.

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So that means this, if you are a Rhode Islander with disabilities and you are under 21,

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And you have a disability that makes it harder to make your own decisions

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Harder to be more independent and to take care of yourself in a manner that society deems appropriate and more likely to get guardianship

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Then you could receive, therapies, support and services designed to increase your decision making and self-determination.

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You could receive equipment designed to enhance your self-determination and services around decision makings.

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Example when I was in the Virginia protection advocacy long before I heard self-determination and Decision-Making

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We had a case where a young man with disabilities wanted a computer.

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This computer was going to help this kid with the school work and manage and plan his affairs.

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What he argued because medicaid wasn't going to cover something just for school work.

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It was equipment to have a specific purpose.

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And what we said this young man was going to use the computer to supervise the billing of his personal caring.

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He needed to approve it was a person centered waiver after all and the waiver said this person is supposed to be the hiring and supervising of the aid

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How can you do your billing without a way to keep track with it.

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We argued this person needed the computer to maximize self-determination and independence specifically with regard to supervising his caring it was covered.

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So what you need to think about EPSDT is ways that specific things can enhance independent and self-determination.

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After all one of the major points and major qualities of the medicaid practice is to help people avoid institutionalization.

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So things that are going to make you more independent and better able to live and survive in the community

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Are natural things that should be covered under medicaid and EPSDT I know that was a fast move through process.

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I recommend talking to Rhode Island about medicaid and the way things are covered. Kate? You're muted.

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KATE BOWDEN: Sensing that you're moving on, I did notice a question that I missed.

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If this is the wrong time to answer it let me know.

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But someone asked if you could provide another example of a scenario where shared decision making is exercised.

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I think that topic shared decision making was new for some of us.

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So where would that come up. If this is the wrong time let us know.

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JONATHAN MARTINS: Not at all. The place that we're seeing the share decision making is in mental healthcare.

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Specifically for people that is in psychiatric crisis that aren't under guardianship

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But may have their decision making ability compromised.

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That is why I'm in favor of power of attorney, it gives me a chance to say now this is what I want to have happened if I become incapacitated

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Temporarily or permanently.

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I have a good friend and she uses them for all kinds of things for people, how to plan what happens in a crisis

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STO say these are things that work for me and these are things that don't work for me

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So I'm not at the mercy of a doctor says I don't agree with you or don't.

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It says right out front this is what I want to have happen I'm saying this while I'm perfectly competent.

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However there's no reason it couldn't apply any where else.

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I'm not going to say it's a horrible thing.

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I'm going to say like everything else it's something we should think about before we jump into it. I want you to be aware of it.

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KATE BOWDEN: Is it like a document or something the medical provider comes with?

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JONATHAN MARTINS: The ladder but you could agree in advance.

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You could say I want to do this, that's the choice right there.

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But where we often see it in psychiatric care.

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If there's parents of kids in special Ed I know you have gone through this.

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You know your kid needs something, needs the support, needs a service or therapy.

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The schools says we don't see that needs at school it maybe something that happens at home

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Or the school says we think two hours of therapy or behavioral therapy is enough because we're not seeing the need for it

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When you know the kid needs for it. That's code for we don't want to pay for more therapy than that.

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Here's the beauty of EPSDT if the school says we will abide by medicaid rules and regulations

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We'll sign up for this. Anything that is medical in the child's IEP any support is paid for my medicaid. There's a link on your screen that shows you could click on and it will say that.

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If a school is medicaid provider than medicaid pays for medical stuff in the IEP and it just has the indicate it is needed for medical purposes. Physical therapy, whatever therapy, this child needs assistant technology, a personal care attendant. What we have

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When that happens is school realize more hours are needed and wrap around services are affective or extended school year services are needed.

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So EPSDT cannot only serve you at home but also in school that support and services are there to help a child that not medicaid.

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It goes beyond healthcare, again when we talk about day-to-day quality of life issues

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One biggest one are finances.

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I always hear the last grate divide is money management and romantic relationships are the two that make the people SWEEMish.

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How can they have relationships, let's talk about money management.

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In fact financial issues are the number two reason I hear why people seek guardianship.

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One, always safety, two is always finances.

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Well supported decision making can help with that TOOCHLT

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on the screen you see language that I did with a mother and her son.

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This person heard me speak and took me aside and said I hear you and think it's a grade idea but I have to get guardianship over my son.

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He can't handle money, he's 18 and at risk of getting swindled.

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So instead of guardianship we set a power of attorney up. That let that protection happen while giving opportunities to learn.

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Here's what we did we said to the young man, we set up a budget you have this much budget a hundred bucks a week or whatever.

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Go nuts. Learn how to spend. Make good decisions.

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Make bad decisions whatever.

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If you want to spend more than that, mom has to sign off on it. If you want to buy a car for twenty thousand you need your mom to sign off.

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So a hundred bucks you could spend you could make good decisions and bad decisions anything more than that you need mom to say okay.

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Here's the important part look at the bottom of the screen we said before mom says yes or no

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Before she agrees or disagrees they have to talk about.

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And give him a chance to explain why he wants to do and she has to give consideration.

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He might be right and if he's wrong it's a chance for mom to talk to him about it.

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It's a chance for them to discuss it.

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You know what I don't think you have the money for the twenty thousand car. Let's set up a budget, let's talk about a job talk about ways to get to that goal

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So the support follows with the plan, mom has to listen to him and he has to listen to her.

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And we have a path forward that will hopefully help him learn decisions in the future.

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Back in the day when people still wrote checks we created a power of attorney.

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You could write a check up to this amount. Anything more than X requires two signatures.

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We see that with businesses all the time. Anything above this amount requires two signatures.

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So that he could write a check up to this amount. But just like before

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Look at bottom of the screen, they had to talk about it first.

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Mom had to listen to the kid, and understand and give him a chance to explain himself.

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Only then can she make the call.

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He might be right and she can sign off. So money is one of those great divide things.

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Money is one of the things that can really be the difference between being independent

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And not being independent.

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Think about it when I say things like community integration, what does that mean to you? Community integration is a right.

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Well so often that is looked at as not living in an institution.

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Well if the only thing that community integration is about not living in an institution and moving in a group home and never doing anything, what's the point?

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You're isolated whether you're in a group home or in a community.

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That has to be more than where you live.

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It has to be how you live.

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How you are apart of your community.

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Going back to the article of faith. How you are acting as a full and equal part of the community

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That's the important part. When we talk about it how do we become part of the communities.

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Where do we really interact with the neighbors and friends, it's when we're working and getting money and spending money.

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True integration is how we live not just the location.

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It's about what we do and the actions we take.

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It's about the vacations we go on and the things we buy and sell and the place we work.

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But that's a problem if you're on benefits.

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So many people with disabilities are on public benefits, SSI, S SDI, food stamps are another.

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These public benefits are the things that really a standing in between people with disabilities and being able to live safely.

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Medicaid a waiver especially often providing the healthcare I need to live independently.

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Medicare S SI and SSDI provide the income we need to buy things we need to buy. Kate?

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KATE BOWDEN: We have a specific question about this money issue

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It came up in the context with the school district but the question if the school district becomes a medicaid provider,

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Do the health care services get billed to the individual or school department or count against the students lifelong cap for the medicaid spending.

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JONATHAN MARTINS: What you are essentially doing is agreeing to allow the school to bill medicaid on your behalf with your policy.

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The question whether it applies to a lifelong cap is a state specific question and I rely to be smart enough to know what I don't know.

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I would recommend talking to DRRRI about that. The school is building medicaid on your behalf on your policy.



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Medicaid is a great example and it's empowering. If you're on a waiver that's one nugget of gold because it can help you live in the community.

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So the last thing you want to do is lose your medicaid. Is lose your SSI, is lose your SSDI. And there's a problem and everyone on public benefits knows it.

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It's pretty much impossible to have a good quality of life on public benefits.

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Here's why you are not allowed to have more than two thousand dollars to your name. That's an income cap. It's two thousand of what is called countable assets.

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You can't own things more than two thousand dollars.

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You can't have people give you things like free rent or car without it counting against you.

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That two thousand dollars is a fiscal cliff because once you go after the cliff at 2 thousand and 1 dollars you are risking losing the benefits.

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So medicaid is your lifeline to medicare you can't have more than two thousand dollars that's scary.

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What kind of life can you have.

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But I hear people say I can't work.

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People that can work and earn money are afraid to work because they are afraid to go over the fiscal cliff that is why I want to talk about a program called ABLE.

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Achieving a better life experience.

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And maybe some of you heard of a 529 account for education

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Allows me to put money in a special account for my child or family member that then grows tax free

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When the kid goes to college or whatever they can take the money out without paying taxes on it P. it's a special account they are 529 for life. If I open an account, I or my friends or family members

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Or anyone can put up to 15,000 a year. That does not count against the fiscal cliff. So remember you are allowed to only have two thousand.

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It doesn't count with an ABLE account and that money grows tax free

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And it can be with drawn tax free to pay for living experience and we'll discuss some later

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And the money in the ABLE account does not count against the physical cliff. I could have up to 101, 999 in my account and it will not count against my fiscal cliff. When you get to 202 thousand dollars

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Your SSI can be suspended but you can still get it.

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The able national resource.org and go there and learn about the accounts and allow to apply for them. It's the eligibility is easy. You are eligible for able if you receive S SD or SSDI

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If you would have applied. If they doctor certified I would be eligible for it if I applied I could get an ABLE account

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So it can be a simple as a doctor doing a certification that I would find this person is eligible for S SDI and that will make you eligible for ABLE account it can tell you all about it you could start putting money in there.

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Up to 15,000 a year to grow tax free.

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Here are some of the things you could use ABLE.

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Those are tiny words because those are the amazing things you could use ABLE for. Almost everything.

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Education, housing, employment support, transportation, bus tickets, car, moving expenses

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Life necessities like clothing, culture activities, vacation, the whole point of ABLE is put people with disabilities in the same situation as everybody else.

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The ability to have a life. I look at ABLE is providing a pathway.

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I know one woman that was afraid to work because of the fiscal cliff.

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This person that called work but put through a lifetime of poverty.

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This woman opened an ABLE account and where it grew. She used that money to get education and job training.

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She took it out of the account and helped her earn more money and helped her put more in the account

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And helped her get a better job. She started at a minimum wage position at a hospital

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And worked herself in a full time job with benefits.

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She didn't need public benefits anymore.

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Is that going to work for everybody? No.

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But what can work for people is having a little bit more money

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Having a little bit more opportunities to do a little bit more things.

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That's the whole thing of ABLE giving people an opportunity for a better life experience of

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You may have heard something of a special needs trust.

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These things work like ABLE with a couple of differences CH

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One special needs money does not count against the fiscal cliff

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But the money is taxable and the big one on the special needs trust is you have to pay for them.

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You have to pay an individual or a bank to manage them.

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But the biggest difference is a special needs trust you have a trustee the bank or person ultimately decides how the money gets spent.

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The person can ask the trustee for money and they can say yes or no.

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In an ABLE account the account holder decides how the money is spent.

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There's nothing wrong with the special needs trust, I have a family member that has it because he can do so many things but can't wrap his head around money.

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I have a niece that uses an ABLE account so what happens with ABLE the person manages money to have a better life experience

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And do more things and in more ways.

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If the purpose is to be more I be dependent and increase opportunities and what better way to do that than making decisions about your money and getting support to do it.

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And you could on ABLE.org and how they involve family members and friends in the process.

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Many states have it in their application where you could identify people front in center who you want to be involved in management of your account

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And how you want them to be involved.

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You could say I want my mom to have access to my account and records. To see where the money is being spent and how.

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I could give my mom access to put money or take money out of the account.

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I could give people just access to see the account.

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I could say part of my disability is I spend too much.

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I'm giving you access Kate to have access to my financial records to see if I'm blowing my budget.

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If I am I want you to have authority to freeze my account if that is what I choose

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The whole point is a since I'm responsible for how the money is managed I'm able to designate how I want support to do it.

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Vocational rehabilitation remember the whole point

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The whole point of VR is to help people work and get ready for a job and get a job back.

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So if you need something or anything to help you work then VR can provide it and must provide it P. and that necessarily includes like healthcare and financial planning.

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If that is deeping you from that, VR can provide it. Of P remember in Rhode Island you have the cap program through disability rights whose entire job is to help people with VR issues

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And you have a great advocate for VR issues and remember that VR have supported Decision-Making baked in the process.

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Every person in V R must receive the opportunity to exercise informed choice it's in the VR allow. ORS must ensure that every person

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Taking part of it's program receives information they need in ways they can understand it,

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So they can choose their job goal, supports and services.

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In other words, supported Decision-Making is all about VR and through that supported Decision-Making you could receive any supports and services



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You need to work just three of them that are written into VRs regulation are things like assisted technology. Medical and mental healthcare and services like day care or health support for an elderly parent or a family member that is not well

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It's directly related to the informed process it's all about supported Decision-Making.

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ORS can also help you with fiscal cliff issues

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They can provide financial support called benefits counseling

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It's there to help me work while at the same time managing my benefits.

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So ORS can provide me with benefits counseling to help me avoid going over the fiscal cliff

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And help me learn about the ABLE accounts and manage the financials to make sure I could both work and keep my benefits. Once again through the use of informed choice and Decision-Making process.

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So that shows you how financial and health issues two of the most important we have in life can help us through supported decision making. Kate?

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KATE BOWDEN: We have a question can a person have an ABLE account and special need trust?

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JONATHAN MARTINS: Some states yes and some don't. I recommend looking at Rhode Island concepts.

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I heard of it and if it's appropriate it's great.

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I know people that transition from one to the other.

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But I would recommend looking at Rhode Island procedures.

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It would be a good thing if you did because you would have more options.

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But understand that everything that we do

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Every decision we make

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Everything we go through in life should have that review.

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Every power of attorney I write, every plan I write includes a growth clause.

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Remember the young man that was 18 and thought he could be swindled.

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We put a clause that says regularly we're going to interview this plan and take a dive to see if it should be changed.

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Our goal is for that kid to be better in managing money.

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The idea is if he is making a better decisions he would up his limit. If he was doing worse we would downgrade it.

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The hope is after a certain number of years he wouldn't need his mom.

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That is something we should have in every plan.

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Now the plans you would have individual plans for employment or individual they require annual review

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I mean a serious deep dive looking at each and every goal and think about what do I need

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Have my needs change?

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That's an important decision making discussion that takes us through life including end of life planning.

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When we're reaching the end of our journey it's important to talk about it.

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It's important to figure out what we want at the end of life.

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And there are facilitated free, processes and programs things called the conversation and five wishes

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That can empower a person with disabilities can make those end life decisions.

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What kind of medication and what kind of music I want to play at my service or if I want a service.

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People might think that sound icky talking about death I thought it was until my dad was reaching the end and he felt better because he had control over something he at no time have control over.

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He got to say what he wanted.

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So I strongly recommend that we incorporated that support in everything that we do.

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What I hope I shown you in this process is how important that decision making is part of our life plan birth to the end of the road.

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We talked about special education from preK and finished talking about end of life planning.

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Supported Decision-Making takes us through it and traces a line through life.

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If we accept and 40 years of study says we have to accept that self-determination makes people's lives better.

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Make sure they have the same opportunities and get the support we all need to do it.

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The studies are pretty clear and the article of faith guides us all through it.

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People with disabilities should and do have a full and equal right to participate in all means of society and their lives.

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We could make that happen by empowering them to have that same opportunity that we have to make decisions whenever we can and get the support we needed.

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And with that I'm happy to answer any additional questions.

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That's my e-mail on screen. Feel free to e-mail me any time.

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I know you have a storm coming and many of us are thinking what is going to happen there.

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I am always available.

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These things have to be discussed amongst ourselves.

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Someone will have a question that someone else dealt with.

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Having those conversations with each other so we could say what works and what doesn't and what we can try.

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I could help you I would be honored. So what kind of questions can I talk about?

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KATE BOWDEN: I'm looking in the chat and not seeing one.

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JONATHAN MARTINS: You could also unmute and talk if you want.

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JOHN SUSAN: This is John Susa. I have a question I would like you to talk a little bit more

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To help parents think about how to respond to the doctor who says well your child has an IQ of 55

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And I don't think anybody with an IQ of 55 understands the implications of this release that he has to sign before I'll do surgery.

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What should the parents say or do at that point?

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JONATHAN MARTINS: Well if at all possible is get a new doctor. That doctor doesn't get and probably isn't going to get it.

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But it's a simple matter I always use the example of Jenny hatch

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Had a tested IQ of 49 and she signed a consent to surgery and is just fine at it.

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Ryan King had a tested IQ less than that. By the way IQ is a terrible measure of decision making.

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Think about every IQ test you ever taken you wind up in a place you never been before

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Talking to someone you never met before, doing things you never before done

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And that's going to determine how well you make decisions.

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I tell this story about Jenny all the time.

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The doctor I took her too, my expert said I tested her IQ it's 49 she can't make decisions.

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We didn't know what to do. The doctor said why don't we go the lunch and goes to lunch with Jenny. She made decisions

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She looked both ways before crossing the street, and ordered her food and everything she was supposed to do.

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Is something that we learn by doing it.

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If someone tells you that a number on a page determines whether you could make decisions that not someone I would want involved in my child's life for one second.

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That is someone that does not understand what decision making is.

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I know it's not always possible to get a new doctor by the way

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But that's how I would answer is how do you know.

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And by the way no one understands that every page of that HIPAA page. You don't have to that's why it's informed choice.

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I make a choice after getting information and that information can be provided by me telling you what's on the form

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Or explaining it to you in words you could understand. Every time you are in the ER look around you a piece of paper with a bunch of faces.

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From happy to sad they use to triage people who don't understand, point to the face that represents how they are feeling.

01:19:52.000 --> 01:19:58.000

That is not understanding every words that nonverbal communication that allows support to help the doctor get the information they need.

01:19:58.000 --> 01:20:10.000

That can be done by someone with an IQ below 55.

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I take that as an opportunity to educate and if you have to understand every word I don't. I'm a lawyer it's about informed choice. What I understand after information

01:20:13.000 --> 01:20:23.000

Not about literally word for word choice.

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If it was about literal word for word choice we would all need guardians.

01:20:33.000 --> 01:20:37.000

KATE BOWDEN: Sometimes it's the an thesologist that wants the consent and you don't know who that is until the day of

01:20:37.000 --> 01:20:45.000

That can be a challenge I don't know if we have an answer for that per say.

01:20:45.000 --> 01:21:01.000

JONATHAN MARTINS: I don't know if I do but ask for policies in advance. I would ask what they do in advance.

01:21:01.000 --> 01:21:15.000

Whenever possible if there's a supported Decision-Making in place I want to inform the doctor ahead of time. If I have a Decision-Making something in write I want it in the file and stapled.

01:21:15.000 --> 01:21:28.000

I want them to know in advance if I have a power of attorney. I was on case in Virginia and they cancelled the surgery

01:21:28.000 --> 01:21:32.000

It's anADA violation and send a demand later and suddenly the hospital realize what they were supposed to do.

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Sometimes you have push back.

01:21:39.000 --> 01:21:52.000

Other questions?

01:21:52.000 --> 01:21:58.000

JOHN SUSAN: I have a related question. I know the social security administration has this questionnaire that needs to be filled out to help make determinations about capacity

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It seems to me that is also a very inappropriate and um

01:22:02.000 --> 01:22:08.000

Not so very useful questionnaire.

01:22:08.000 --> 01:22:14.000

How do you -- how does someone challenge the use of that?

01:22:14.000 --> 01:22:24.000

JONATHAN MARTINS: I missed we had a connection hiccup. Can you restate the first part again.

01:22:24.000 --> 01:22:34.000

JOHN SUSAN: I don't know what it's called but Social Security has a questionnaire that they use to determine whether somebody is supposed to have

01:22:34.000 --> 01:22:47.000

A representative payee or whether my can manage it themselves.

01:22:47.000 --> 01:23:03.000

JONATHAN MARTINS: Actually Social Security issued a report some years ago because I testified in the investigation where they are supposed to de-emphasizing the payees

01:23:03.000 --> 01:23:11.000

And it is an which will of how to avoid a payee another thing that Social Security is supposed to do is give people the opportunity to have someone on the phone with them.

01:23:11.000 --> 01:23:22.000

Yes my mom is on this call so the person can receive support through the whole process.

01:23:22.000 --> 01:23:25.000

It can be something that can avoid guardianship so I'm not discounting payees but it's also an opportunity for supported Decision-Making through that questionnaire process

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But also through the entire Social Security process.

01:23:30.000 --> 01:23:34.000

So I strongly recommend having a supporter on the calls

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So announce to say you are going to have one.

01:23:47.000 --> 01:23:57.000

KATE BOWDEN: I'm not seeing anything new in chat.

01:23:57.000 --> 01:24:04.000

JONATHAN MARTINS: So if someone else has a question feel free to ask. If not, please remember my e-mail that I'm going to put in the chat WOKS

01:24:04.000 --> 01:24:06.000

Box and you should feel free to reach out to me any time.

01:24:06.000 --> 01:24:08.000

Hopefully I type that correctly.

01:24:08.000 --> 01:24:18.000

Feel free to reach out.

01:24:18.000 --> 01:24:33.000

I'm looking forward to talking next time, our next presentation is a sum up of the things we learned thus far

01:24:33.000 --> 01:24:44.000

And ways to bring them together to create a more effective system we're going to show you how we could fit supported Decision-Making to have the programs you heard about work together.

01:24:44.000 --> 01:24:50.000

And one thing I'm looking forward to talking about is something that we don't talk enough about is ways that supported Decision-Making can help people be more involved in their which you know thes

01:24:50.000 --> 01:24:57.000

And more involved in KIF I cans.

01:24:57.000 --> 01:25:08.000

Think about voting, people with disabilities vote far less, this is a great opportunity for education and experience

01:25:08.000 --> 01:25:17.000

And I know disabilities rights Rhode Island is doing interesting work around decision making.

01:25:17.000 --> 01:25:23.000

KATE BOWDEN: Thank you so much Jonathan and thank you for being available despite your hardships and we appreciate it so much

01:25:23.000 --> 01:25:27.000

And look FARD to our next time together.

01:25:27.000 --> 01:25:33.000

JONATHAN MARTINS: Thank you very much and hope you all stay warm. Bye-bye.