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Session 5: Bringing it All Together: The Culture of Coordinated Support Model
with Jonathan Martinis
January 27, 2022
6:00 PM - 7:45 PM (ET)

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(Captions provided by a live Captioner.)

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MORNA MURRAY: Good evening everyone and welcome. My name is Morna Murray, I am the executive Director at Disability Rights Rhode Island. I'm really happy to see all of you tonight. I know many of you have been with us during this webinar series. It is bittersweet to be coming to the final session tonight with Jonathan who at this point needs no introduction. And probably someday no introduction anywhere since he is so good at what he does.

I want to say Jonathan is a real expert at supported decision-making and not only is he an expert but he is an incredibly good lawyer and advocate for people who need it. We were just talking about another case he won recently which is fantastic. I want to turn it over to Jonathan and say thank you, thank you, thank you for being with us on these successive nights and for being with us tonight to pull it all together.

I am happy to see so many people here. As usual it will be posted on the website and as usual Jonathan will interrupt himself at any point for questions.

I will direct them to him. He will stay after for questions and we will be talking with him about whether or not we might have further presentations on supported decision-making in Rhode Island. But with that I turn it over to my wonderful colleague and very dear friend, Jonathan Martinis.

JONATHAN MARTINIS: There is 0% chance I can live up to what you said but thank you so much for saying it. To everyone who has been with us on this journey for now the fifth webinar we have done together. Thank you so much for being with us to learn about what I think is the most important advance in human and civil rights for people with disabilities since the Americans with Disabilities Act.

For those of you who are new or have not seen all the webinars, please check them out on Disability Rights Rhode Island's website. They are all archived there. There are amazing things you can find on the website as well. Resources that can help you and the people you care about access the services and supports they need, want and deserve to live their best lives.

What we will talk about today is two things. One, we will do a summary. We will bring together all the things we talked about so far. To me the first two most important things we can do with supported decision-making is use it in a coordinated consistent way to make sure the services and supports people need to access their best possible lives are available to them consistently in a way that is efficient and effective.

Two, we are going to talk about a new model that we can use to make sure those supports and services are delivered consistently.

With that, let's begin.

What we will talk about today is what I call the Culture of Coordinated Support. It starts like this. What we have to realize when we are talking about a model or anything each and every one of us wants the same things. Everyone watching this, everyone watching on video, anyone who is never heard of supported decision-making wants the same thing.

That is this. We want the lives we want. We want to do the things we want. We want to have things that meet our values. We want the relationships we want. We want to work and have opportunities that speak to us make us feel unique and individual. In other words, we all want to be self-determined. That is what Self-Determination is.

As we have said again and again and again people who are self-determined make more choices and do more things. They are the causal agents in their lives. People who do things rather than having things done to them. To make choices rather than having choices made for them.

What we know from 40 years of studies is that people who are more self-determined have a better quality of life. Let me repeat that. People who are self-determined, and this is not up for debate, we have studies going back to the 1970s, people with disabilities who exercise more Self-Determination, who make more choices have a better quality of life.

They are more likely to be independent, educated and employed and have more health, happiness and safety.

How can we get there? To me the key way to get to Self-Determination is through Supported Decision Making. The long definition is on your screen. You all heard me say I don't care for this definition very much. What I can tell you about supported decision-making is this. It is getting the help you need to do the things you have to do.

That is it. It is the help we get every single day when we ask for advice, when we do research and again I say think of all the clichés about decision-making. Get a second opinion, don't go off half-cocked, make an informed choice, measure twice and cut once. They all mean the same thing – get help.

Because when we get help, we are better able to make informed good choices. When we get the information that we don't have that we do need, we are obviously going to be able to make our best choice.

What we know from research now is people who use supported decision-making have more Self-Determination. Hardly rocket science, is it? If I make more choices using support rather than having someone make choices for me, I am almost by definition going to be more self-determined.

And what we know Self-Determination equals a better quality of life. We show that in three studies in Virginia where we worked with young adults to create and implement their own supported decision-making plan and followed them for a year.

The data we collected, the people we talked to led to one inescapable conclusion. The people who used Supported Decision Making were more confident, independent, were better at making decisions and according to the people in their lives made objectively better decisions.

And even made with the pandemic and had a better more robust quality of life. With all of that as an introduction, a question for you. If you feel self-determined, if you feel like your life or you are in control of your life or you are satisfied with the level of Self-Determination, how did you get there?

How did you get from where you begin to a place where you feel at least decently in control of your own life? You did not do that by yourself. If we went around this room each and every one of you had that one person, teacher, mentor, one moment to put you on the path.

The person who helped to figure out what you wanted to be. The person that crystallized the goals for your life. Maybe it was the person who helped to write your first resume or get your first job. Maybe it was a mentor to help you figure out a path that was right for you.

Here is a sad and perhaps unsurprising truth, if you are a person without disabilities as I call it a temporarily able-bodied person because we are all one second away, one diagnosis, accident, slip, fall, heart attack or stroke away from having disabilities so if you are temporarily able-bodied getting to Self-Determination was not that hard.

You are part of the system. You are part of the system so effective and efficient you do not know you are part of it. But if you think about it for a second it makes sense. People without disabilities lives progresses more or less in a linear fashion. You have school and you have teachers where you learn and you learn and go to the next step.

You might go to college or trade school but that leads to a job or a guidance counselor helping you figure out a path with the job, mentor, goals. Perhaps the house, perhaps a family. But you are going forward. You're going forward because the steps along your path are laid out.

There is a linear progression. As each and every person on this call almost certainly knows there is no such path for people with disabilities.

For people with disabilities and their families it is a frustrating path and a confusing path. For people with disabilities, it is in every state, you are sent over there to that person and the agency to talk about education stuff. You are sent there to that person or agency to talk about unemployment stuff. Healthcare is over there and money management is over there.

What happens is you are running around and you learn a sad scary thing. That person doesn't know that person or that person doesn't like that person, or that person is a competitor of that person. So what happens to people with disabilities and their families? Instead of the linear path, they spend so much time running around trying to figure out who can provide services and what services are available that they never had an effective opportunity to get those services.

What happens to a person with disabilities when because the system fails they are not able to achieve? Does society look at the system or does society look at the person? What we know for 1500 years is society looks at the person and says you can't.

It does not matter the system broke down, society says you can't to the person and that leads time after time leads you towards losing rights through guardianship. We are sitting at a time with three times as many people in guardianship as there were 25 years ago.

What happens is when the system fails, people lose their rights. We need a new way. We need to get away from what experts call a fragmented system. One that sent you in different directions. I had an article with a partner and we call it a silo system. Education is in a silo and employment is in a silo. They do not speak or work with each other.

We are at a time now and the sad irony of silo-ed systems is this one every agency and support system is being asked to do more with either little funding or less money. They’re asked to serve more people and have less resources and employees to do it. When the system is silo-ed, when the system is fragmented, they're wasting resources.

Let me give you a sad and scary example. I gave a presentation in Missouri. What happened afterward was a grandmother called me she said Jonathan I buy into what you said. I agree with you and I don't think guardianship should be rushed into but I have to seek guardianship over my grandson. He cannot make it. He is flunking out of school. He cannot hold a job. There's no way he can live independently. I have no choice.

Then I asked her who is he getting services from? She said he has special education so he has an IEP. Has vocational rehabilitation. Is a Medicaid waiver so he has ISP. All of those services and supports, in fact, almost every support available to people with disabilities does essentially the same thing. All of those. Special ed, vocational rehab, Medicaid waiver, Centers for Independent Living. Required by law to focus on the same things.

Broadly speaking they are required to have goals, objectives, supports and services around education, employment and independent living. I asked the grandmother to please send me the plans. She did. I got those three plans. They all had goals and objectives around education, employment and independent living. None of them matched. Not a one. For education they went everywhere from GED to maybe a four year degree with the support.

For employment one of them said, hand to God, one said he could be a full-time employee with the job coach for independent living everywhere from group home to supported department. I said to that grandmother of course your grandson is failing. How can he succeed? How can anyone succeed when three agencies were supposed to help them are pulling him in nine different directions?

It is impossible to succeed because their goals, objectives, supports and services are canceling each other out. They were pulling in different directions. How much money got wasted? How much of your tax dollars was wasted because they cannot work together.

That inspired me to think about we need to change this culture. You heard me talk a lot about culture. I will talk more about it.

We have a culture not just of guardianship for 1500 years. We have a culture of silos. We have a culture of separation. We need to break that down. What I will talk about today is a new culture. A culture of coordination, a culture of collaboration.

Here is my promise to you. It is already required. Remember how I began the first time we were together I said everything I talk to you about is backed by law and science. Everything I will tell you that should be done and recommendations I have are already required. Let's talk about the culture of coordinated support. That is what it looks like.

This picture comes from Ohio. I was giving a presentation about this theory. Afterward a gentleman walked up and said I'm a visual learner. Is this what you are talking about. I told him if he colored it in I would take it and use it from now on. So thank you to Pete

Moore from Ohio for this amazing depiction of what the culture of coordinated support is.

Look who is around and the person in the center. Her education system, employment, VR, waiver system, DD and her family. They are talking to her and giving information to her and from her. That is what they should be doing, Person Centered Planning. Look at the connections between agencies.

They are talking to each other. They are getting information from each other with her permission of course. By doing that they are breaking down the silos. By sharing information, by sharing resources.

Here's the thing. I've told you each of the agencies have to deal with the same thing education, employment and independent living. I do plenty of training for teachers and I asked them did you get into this field to be an employment counselor? No, we got into it to teach. I asked vocational rehab counselors did you get into this field to teach? No, we got into help with employment and independent living.

The law requires them all to address education, employment and independent living. Why did they have to do it from silos? If they work together like you see on the circle. If they share information with each other teachers can teach. Vocational rehab can focus on work. Centers can focus on living. Why are they having three separate meetings.

I hear time and time again having the meeting is the hard part. Scheduling a meeting and getting everyone together is the hard part. Why are we having three separate meetings with three separate plans they all have to deal with the same goals. In fact, you will find out all the plans have a section called related services or other.

Wouldn't it be great if an educational IEP could say yes, I know we have to deal with employment attached you will find Jonathan's IPE which addresses his employment goal and his supports and services being provided by vocational rehab or the waiver case manager can say I know we have to deal with education attached is Jonathan's IEP.

Just like that each can focus on what they do well while keeping track of what else they have to do while someone else who specializes in it is doing it. Just like that outer circle they are working together.

They are communicating with each other and cooperating with each other. They are working from a shared vision that came directly from the person because by meeting together and having the goals and objectives that she identifies they will not be doing diametrically opposite supports. That is what we need to do.

That is why communication and coordination are so important. Consider the way that different entities could deal with a different concept.

Let's say she says her goal is she wants to have her own apartment. Her education provider could address independent living or community programs that can help her do better at daily living skills.

Remember I showed you and I will show you again transition planning is supposed to include acquisition of daily living skills. So the school can focus on the daily living skills needed to live in an apartment. Vocational rehab can focus on getting a job getting the supports and services needed to earn the money to pay rent.

A Board of DD or a DD waiver professional can help identify independent living supports like healthcare management and transportation that can help her live successfully in that apartment. Just like that, by splitting up the responsibilities into their own sphere what they do well we are doing better.

What I will show you and what I already showed you over the last four webinars is supported decision-making can link all of the supports and services together.

Supported decision-making can be the arrows going from her to the agency and the agencies toward each other because we are going to show you as I have shown you that SDM is the common tongue between these agencies. It can and should be the linkage because of the coordination and collaboration.

It can happen at any age. It is a school age child in a school and DD provider can provide… Vocational rehab can come in and provide employment. If it is an adult, you can have a center for independent living. They collaborate on budgetary management, independent living and work. The possibilities are endless.

The key simply is this: Communicate, collaborate and work from a shared vision. That is going to increase efficiency, decrease redundancy. Make her supports better, make agencies resources last longer.

As I said, supported decision-making is what provides blank. I showed you and I will show you again. The student led IEP, special ed, informed choice, Person Centered Planning these are all permutations of supported decision-making. What I'm telling you is all these agencies working with people with disabilities are required to do the same thing in the same way.

Let's talk about how they can do it. Quick review what we know from special education and what I have said before special education is where we first learned to make decisions outside of the home. We know special education is required to provide services and support that are reasonably calculated to provide educational benefits.

What are educational benefits? They come directly from the law. Look at the bold language. Every special education program is required to prepare students for further future education, employment and independent living. What do we know is the key component? What leads directly to a better opportunity and better results in education, employment and independent living? Self-Determination.

Which means Self-Determination and decision-making should be in IEPs from day one as early as possible. DC Public Schools has a in pre-k. When we are doing an IEP and when we are creating IEPs with goals and objectives and goals and objectives as we discussed in our second webinar should build Self-Determination.

We know students who lead their IEP meetings have more Self-Determination and do better in class and out of class. We know students who have goals that are focused on enhancing Self-Determination have more Self-Determination and do better in and out of schools.

We should be encouraging and empowering students to take control and make decisions. We can do that through IEPs. Through the student led IEP. The gold standard for the US Department of Education. The student leads the meeting. The student to the maximum of his or her abilities consistent with their age.

The responsibilities can increase over time. A three-year-old can just say hi. A five-year-old can say what their favorite class is. A seven-year-old can say what they like and don't like. The idea is as the student gets older they take on more responsibility. The student sets the agenda. The student introduces the room. The student talks about what works or does not work. What goals he or she likes.

The goal being at age 18 the student is the leader of the meeting. The student works with the IEP team collaboratively as one expert says practicing in a safe environment to make decisions so that the team collaborates with the student, the student works with the team, together they develop goals and objectives. Together they develop what we described as "I Statements" and Self-Determination goals so that at the end the student and team have agreed upon goals and objectives and the student can sign it.

In other words the team supports the student. The student decides to sign the IEP. Does that sound like Supported Decision Making? Isn't that exactly how we describe Supported Decision Making? It does not end there.

When the student turns 14 that student can take part in what we call transition planning. To me, the most important part of the IEP process, transition planning is there to help the student prepare for the rest of his or her life. Special ed ends at 21. Life goes to 81 or 91. In transition planning you are planning for the rest of that student’s life. Look what transition planning is supposed to include.

So many people have told me transition planning happens at the end of the IEP meeting. They ask the student if they want to go to college and refer to a guidance counselor. Do you want to work and if so refer to VR. That is not transition planning. What is on your screen comes directly from special education law. From the Individuals with Disabilities Education Act.

First, for purposes of the culture of coordinated support, transition services are required to be coordinated. Second, look at what is required. They are supposed to provide education, employment, and independent living. So to facilitate the movement from school to post school activities including further education, further employment, for the independent living and supposed to build adult living objectives and daily living skills.

But all the things we all need to be employed, to be educated and to live independently, I have said it before and I will say it again. What is a more important daily living scale or adult living objective in making decisions? Transition planning is exactly when we should be focusing on decision-making.

We should have begun it in pre-k. It should be focused laser-like in transition. In the District of Columbia they begin a formal supported decision-making process identifying supporters, areas of support in ninth grade so that by 12th grade by age 18 they are authorized to sign, if they choose, a supported decision-making agreement saying this is my team. I want them in my IEP meeting. I want them to have access to my records so we can work together so I can plan the best education.

The best future plans for me. Thereby solving the problem that so many parents have said the school saying if you don't get guardianship you cannot come to an IEP meeting. Which is just completely wrong by the way. Anyone can come to the IEP meeting. The person makes that choice. With supported decision-making the person can make a formalized choice and practice engaging in a supported decision-making process.

You have minimum five years. IDEA says transition starts at 16. In Rhode Island you can start even sooner. In those years you have this wonderful opportunity to coordinate services, to build community experiences, to coordinate the acquisition of daily living skills including supported decision-making.

Look, there's a lot on that page. School people tell me all the time there is a lot there. We don't have the resources to provide, for example, community participation programs we’re linking to adult services. We don't have the time with all of our curriculum requirements to focus on integrated employment.

But I will tell you, transition is coordinated. Transition should be coordinated and wouldn’t it be great if there was a way to coordinate to make sure, like I told you the school can focus on teaching?

There is. Vocational rehabilitation. The subject of our third webinar. Vocational rehabilitation number one is available to anyone at any age. I’m discussing it out in the context of transition planning to show you schools have another option but vocational rehab is open to anyone at any age.

You can be 90 years old and qualify for vocational rehab because it's all about work. It is about the services and supports people with disabilities need to work. If you are a person with disabilities and you need something to help you prepare to get a job, keep a job, advance in a job or get a job back you should get it through vocational rehabilitation.

When we talk now about independent living and sometimes guardianship, the question I have is what if the same things that are stopping you from working to the maximum of your abilities are also the things that are making it harder for you to learn and are also the things that are making it harder for you to live independently. Also the things that are driving you to guardianship.

Things like inability to take care of yourself and medical needs, interpersonal issues, communication skills or disorganization. What I have heard from VR is those are not work skills. Those are living skills and someone else should provide them.

What I have told VR in more than one case as this. Would you hire somebody who is so disorganized they cannot follow your policies? Would you promote someone who has such poor interpersonal skills they get into fights with your customers or clients? Would you retain someone who takes such poor care of him or herself that they are getting themselves sick and their hygiene is getting others ill?

Of course not. That means independent living skills, life skills so long as they are also limiting employment skills are things that VR can and must cover. So when we are talking, for example, about transition when the school says how can we do employment? How can we do all these things? The answer is VR can do them. VR can help with all of those. And there is so much that VR can provide.

I told you all about my favorite regulation in the world. 34 CFR 361.48. This says all the things VR must provide. Look at these closely. Often we're asked people to name something that stops people with disabilities from working. In about a millisecond five people say transportation. Transportation is on that list. VR must provide transportation if that is stopping someone from working. Take a good look at the list.

But what is on it? Education they have to provide. Employment, job coaches, job counseling, internships, independent living, medical and mental health care, services to family members. Doesn't that sound a lot like what has to be provided in transition. Employment, education, independent living, vocational assessments.

What I'm telling you is when you are working with the student, for example, you have two agencies that do the same thing and provide the same support and services. It does not stop there because VR also has to provide the same way that schools do. Just like the Student Led IEP. VR has the informed choice process. Informed choice where my counselor's job is to advise me, support me and give me information.

To give me recommendations about job supports and services and providers. The idea being my counselor has knowledge I don't. They know what the job market is like. They know what the providers are like. I know what I want as the client. The counselor is supposed to help me figure out how to get there. Provide me with information, advice and resources so that I can design my job goal.

I can choose my providers. And I can agree to my goals and objectives. My counselor, just like the IEP team, advises, supports and I sign off and decide. Isn't that just like

Supported Decision Making? Isn't that just like the Student Led IEP. In the context of transition planning, we had to introduce the do the same thing and speak the same language.

Why are they in silos? Why are they not working together? Why are they complaining as they often do about a lack of resources? Why are they using a lack of resources as an excuse to not provide services when they can and should be leaning on each other.

They must work with each other. I already told you the culture coordinated support is already required. On your screen right now are the laws relating directly to VR. They say this, number one, pursuant to a funding law called the Workforce Innovation and Opportunity Act, VR receives lots of money on the condition that they must provide significant emphasis on providing services to young adults with disabilities.

Two, federal law has had for decades that VR must become involved in special education "as early as possible". My favorite regulation 34 CFR 361.48 says VR must attend IEP meetings if invited and they also must attend waiver meetings if invited. Not only is coordination a good idea but it is provided by law and perhaps the farthest reaching coordination Pre-ETS, preemployment transition services.

Pre-ETS as I have told you are available and must be provided by VR to each and every transition aged student with a disability. Every student with an IEP. Every student with a 504 plan. Whether or not they are a VR client. VR must seek them out and work with the school to identify them.

And they must provide far-reaching supports and services to them. Take a look from the regulation, my favorite one by the way, this is the first thing you will see in 34 CFR 361.48. It will tell you VR must provide to every student within transition age with a disability job expiration counseling and help them identify possible jobs later in life. Workplace learning experiences like internships, in school training, a lot of school opportunities so they can learn work skills.

Counseling on education, post secondary college training. Workplace readiness training to develop social skills and independent living skills. Why? Because we already know from before social skills and independent living skills are critical to employment. And Self-Determination flows through all of them.

Finally instruction in self advocacy to help you exercise Self-Determination better.

These must be provided to each and every student of transition age whether they are a VR client or not if they have a disability or not. Lastly, that regulation makes it clear VR gets invited to an IEP meeting and they have to come.

Coordination and collaboration is not morally right. It is legally required. It is not just an effective practice. It is a required by law practice. You as parents and advocates should be pushing this.

The first thing I would ask when my kid gets to transition age I would be asking the school what their Pre-ETS policy is. If the school looks at you like you have three heads and importantly sometimes they do, I would show them this regulation. I would show them the regulation and say there is a majority who have to do school why isn't VR involved doing this with us?

After education and employment there is still a huge segment of life. Independent living, healthcare, the things we need to do to live successfully in the community.

If you are receiving anything funded by Medicare, Medicaid, the center for independent living, anything where you hear the phrase Person Centered Planning this is another opportunity for coordination, another opportunity for collaboration required by law.

Person Centered Planning by definition, and I cut and pasted this from Medicaid.gov, it is a plan that reflects the individual's preferences and goals. Look at what it is centered on. Education, employment and all of those independent living requirements healthcare and wellness, incoming savings, community participation. Community participation, employment, education.

Doesn't that look a lot like what we saw in 34 CFR 361.48 VR? Doesn't that look a lot like what we saw for special education transition planning? If you have a young adult in transition someone in special education who is receiving special education then you should be using these Medicaid services if you can possibly get them. If you can possibly become eligible for Medicaid either state plan option or a waiver because these plans now are covering the same things.

They are another avenue of access for supports and services. Not only are they covering the same areas, they are speaking the same language too. Anyone who's ever gone to Person Centered Planning training, I apologize, knows this about Person Centered Planning. You have to determine what is important to the person and what is important for the person.

The Person Centered Planning is supposed to find out where the person is now metaphorically where they want to go. What the person wants to keep the same in his or her life and what they want to change so they can figure out the short and long-term living objectives and the counselor's job in that one is to help guide the person through it.

Help the person understand and learn what he or she needs to live independently. So that the counselor provides advice about potential objectives, activities, providers. So the person can choose his or her short-term or long-term objectives and the supports and services and providers that they need to get there.

Counselor supports, person decides. Isn't that just like supported decision-making? Is it not just like the student led IEP? Is it not just like informed choice in VR? For coordination purposes know this, if you have a student who is receiving Medicaid and is in special education your best friend is Medicaid.

How many times have you heard from a school, all of you had it happen to you or heard the horror story there's a support and service everyone knows that student needs. Some therapy, some occupation therapy, physical therapy, speech therapy, behavioral therapy, some assistive technology something to help that student but the school will not cover.

The school will say in code language we are not seeing that in school or we do not see the extent of that we can offer you two hours of therapy a week when everyone knows more is needed and God help you if you ask for summer services or wraparound services.

I feel bad for the school because of course resources are low but here's something for you to know. If a school becomes a Medicaid provider, that is a paperwork exercise. If a school becomes a Medicaid provider for the state Medicaid system then any health related item in an IEP for a student receiving Medicaid is covered by Medicaid.

Let me put that another way. If the student is getting Medicaid State plan option Medicaid waiver, whatever you have. Students receiving Medicaid who has an IEP, health related item and anything can be described that way, will have it paid for by Medicaid if the school becomes a Medicaid provider.

That is an incredibly powerful option because schools now have a funding source. Schools do not have to play the game of we do not see it or offer less than you know or not offer wraparound or some other services because they have a funding mechanism.

When I talked about this in Virginia years ago all the schools signed up because then they did not have to spend their resources, they could spend Medicaid's. Is a coordination opportunity when you are doing the IEP and considering supports and services if your student is getting Medicaid make sure you ask that school not just about their Self-Determination system but whether or not they are Medicaid provider.

Whether they know if they become a Medicaid provider they have a funding stream that can support them.

Otherwise we can find individual supports and services. I told you I just gave the context and the idea of a student to understand people out of school can use the culture of coordinated care plan just as well. You can have VR and a waiver working together or VR in the center for independent living. If you don't know Centers for Independent Living you should. They are funded to serve specific communities.

There is a Center of independent living covering sections of every state. You can find yours at the website on your screen. You can Google center for independent living in your town. It will show you the closest one. The point for centers of independent living is to help provide supports and services to people with disabilities that they need to live independently. That they need to promote their self determination. To promote equal opportunities and respect in the community.

The amazing things about CILs is bylaw majority of employees must be themselves persons with disabilities. If you are a person of disabilities working with a CIL, you can receive peer mentorship, service supports, advice, assistance from someone who has done the things that you want to do.

You can learn supported decision-making from people who use Supported Decision Making. You can learn to navigate the system for people who have navigated the system. It is an opportunity to learn and practice the skills you need. A center for independent living is available to anyone of any age as long as they have disabilities.

Again, while I showed you that schools, VR, Medicaid providers can work together it works just as well if it is a CIL Medicaid VR for someone out of school. We can find ways to have these entities work together because again supported decision-making is the common tongue. If at some point in your life you have to make decisions, and we all do, and if you are a parent trying to help your child make the best decisions, and we all want that.

Then supported decision-making is a way you can do it. We know there are powers of attorney we can write. And a power of attorney is just me saying to you saying to Morna God forbid something happen to me I want you to make decisions for me. That is what a power of attorney is. We choose the person we want to make decisions as opposed to a guardianship where the court chooses.

We choose how those decisions are going to be made. I can say to Morna God forbid something happens to me I want you to make decisions for me but here is how I want you to make them. Look at the bold language. I am giving you power. I want to retain as much control over my life as possible but I'm giving you the power to make certain decisions. But before you make them you will talk to me first.

You will give primary considerations to what I want before you make that decision. We can do that in medical care. God forbid something happens to me I want you to make my medical decisions but you will consult with me first. In fact, we can put in a power of attorney there are certain decisions you're not allowed to make. And I never authorize you to consent to me getting electroconvulsive therapy.

I never consent -- I never agreed to you consenting to me being shot up with Haldol. We can also in advance directives say what happens when we can make decisions.

On your screen I can say to Morna God forbid something happens to me I want you to make decisions for me. In the meantime while I can make decisions I want you to come to the doctor with me.

I authorize you to come to the doctor with me so at times when you do not have power to make healthcare decisions you still are authorized to come to the doctor with me and provide me with support so that I can make healthcare decisions to the maximum of my ability so I understand the doctor and he understands me.

I authorize you to be in the room. Just like that you have made a legally enforceable advanced directive covering decision-making in medical care both when you are unable to make decisions and when you are able to make decisions.

The same types of support can work in the financial world. Finances are the number two reasons I hear why people seek guardianship. Number one being safety. I've shown you before that Self-Determination is correlated with enhanced safety. We can also use Self-Determination to teach financial management.

The story I told you the last time was an 18 year old whose mother thought he could be swindled and was going to get guardianship to make sure he did not make bad financial decisions.

What we did over the course of the year is we created a power of attorney, language on your screen now, where we said to that young man you are an allowance of X dollars a week or month go nuts. Go learn how to make decisions make bad decisions and good decisions. Learn what it's like to have money and to use it. What money is worth, what you can buy with it and what you can't living on a limit.

If you want to spend more than that mom has to sign off. If you want to buy a car for $20,000, mom has to sign off on it but we put supported decision-making. If that kid wanted to buy a car mom could not say no. She had to talk to him about it. She had to listen to his reasons and consider his expressed wishes before saying yes or no. One, he might be right. If he is right, she should sign off.

But if he is wrong, more importantly, it gives her a chance to support and teach. Maybe it gives her a chance to talk about budgeting and set up a spending plan or a savings plan. To talk about just how much he needs to earn and save to get to that $20,000. And just like that instead of it being a yes or no issue it becomes a learning moment. That young man received support so he can learn about budgeting and financial management so that he can make decisions, better ones in the future.

When it comes to finances, we talked about ABLE accounts. I want to touch on that because ABLE accounts come up to me in the most important contacts and that is work. So many people with disabilities who receive benefits are on Medicare, Medicaid, SSI, SSDI and food stamps are free to work because they are told they cannot work. If they do work, they will lose their benefits. And that's a legitimate fear.

The benefits are the things that keep you living in the community. The healthcare you need, the service and support you need. You are fighting not to lose those.

What they are told and what is legally true is if you are receiving the benefits you can't have more than $2000 to your name. We call $2000 a fiscal cliff because once you go over it you are at risk of losing benefits. People with disabilities and families are afraid to work.

They are afraid to have money. ABLE accounts are a way for people to have money. They are a way for people with disabilities to work. As I told you the last time, we were together, an ABLE account is a tax-free account. It’s a tax-free special account for people with disabilities who are eligible and you are eligible if you receive public benefits SSI, SSDI, Medicare, Medicare food stamps or a doctor certifies you would be eligible if you apply. So once you are eligible for a ABLE account

you or someone on your behalf can put up to $15,000 a year in the account. The account can be used for just about anything. It can be used for so many things. It grows tax-free year after year. It has no impact on your benefits.

You don't go over the fiscal cliff. It has no impact on your benefits unless and until there is $102,000 in the account. When there is that much money in the account SSI is suspended but Medicaid continues. There is $101,999 in the account the person stores use of benefits and that money can be taken out for just about anything. All these tiny words on the screen are some of the things that ABLE can pay for.

Take money out of the account to pay for education preschool through college, school, housing, rent, mortgage, home improvements. It supports anything associated with getting a job. Transportation to and from work. Things you need at work. Healthcare things. Healthcare premiums. Classes. Assistive technology. Transportation. Taking the bus, taxis or Uber. Other life necessities up to and including recreational activities.

Part of having a life sometimes is to have a vacation. To learn more about it I recommend checking out the website www.ABLENRC.org. It has all kinds of info on qualifying for it and finding supports and services and things you can use it for.

To me the key component of ABLE is the person with disabilities who has the account has to decide how the money is managed. That person decides how much goes in and how much goes out. That person decides how to manage the money. That means the ABLE accounts entire purpose is to maximize independence and quality of life. What do we know is directly related to that? Self determination.

What is this a perfect opportunity for? Supported Decision Making. With an ABLE account I can authorize people to have access to the account. I can authorize if I want to have different levels of access to see the balance and from overspending to put money in or put money out. My choice. I can manage the account with the assistance of a support. Doesn't that sound like anyone?

Supported Decision Making follows us all through life. One of the key parts of life and something that people with disabilities do not do enough is voting. It is an incredibly important part of life. I don't want to go on a sermon about this but I asked before when the concerns of people with disabilities will finally get taken seriously by our elected leaders.

My answer has always been the same. When people with disabilities swing an election and a vote in a way that is a difference maker in an election. I never tell people who to vote for or how to vote but I say vote. Find the issues important to you vote and vote loudly. Let people know how you voted, when you voted and who you voted for so the politicians and influence makers know that people with disabilities vote and theirs should be respected.

When we vote we vote with the support. Voting is the ultimate making of choices. We all use supported decision-making when it comes to voting. We all do research. We talked to friends and family members. Over the last six years there has been too much talk about voting in ramifications. Families have broken up over this. But it doesn't change the fact that that is what supported decision-making is all about.

It is about getting the input. It is about having the discussions. It is about getting the access to information. People with disabilities do the same thing in the exact same way that we all use supported decision-making to make decisions in life. We use it to make decisions about voting. That is hugely important because people with disabilities can and should vote.

Under Rhode Island law even people under guardianship retain the right to vote unless the court specifically removes the right.

That is different than, for example, Virginia where I live where you are presumed to lose the right to vote if you are under guardianship.

You are presumed to be incapacitated. In Rhode Island even if you are under a guardianship check the order. If it does not say you have not lost the right to vote you should be part of the political process. People with disabilities should be using supported decision-making just like everyone else. But the supporters can really be a key for people with disabilities. They can help a person learn about ways to cast their vote, the options, in-person voting, curbside voting, absentee voting.

They can make a plan to vote. So often it's hard to get to the polls or schedule transportation or schedule leave from work. Learn about accommodations to help you vote. Accessible voting, accessible ballots, assistive technology. What about getting a sample ballot sometimes it's as simple as that getting one from your Secretary of State so you can learn who from the people are and you can research the candidates and what the issues are that are on the ballot that year and learn about them.

I went through Disability Rights Rhode Island's material they have some of the most impressive, and forgive the terminology, aggressive. I agree it is aggressive voting rights material. Aggressive meaning it being very clear that these are your rights and you should exercise them. Don't let anyone take them away. Don't let anyone stand in between you and your rights. Disability Rights Rhode Island has a year-round hotline or you can connect them with questions about voting.

Questions about how to register, questions and concerns about the voting process, understanding your right to vote and how to exercise your right excessively and privately. They provide training to groups about topics around voting. Not telling you how to vote by the way not advocating a particular position. The only position they advocate, like you just heard me say, is vote.

These are your rights and you should not lose them. I cannot think of a less American thing then and inaccessible polling place because when you have a place but a person with a disability cannot get into or a ballot a person with a disability cannot access you’re telling the person you are not a citizen. You cannot exercise the most basic privilege of citizenship.

Not because you are unable to do it but because we won't let you do it because we have not taken the time to make sure you can do it excessively.

They also have information and resources on their website. You can go to under the resources section. Look under publications. I'm sorry for sounding like I'm making a commercial for Disability Rights Rhode Island but I am incredibly impressed. When I worked for the advocates in Virginia we had nothing like they have.

I think it is fantastic and you are doing yourself a great favor if you look at it and take them up on their services and supports.

Finally, the end of the journey. The Conversation, Five Wishes other facilitated processes to help people make end-of-life decisions. I know I mentioned this last time but like so many others I felt it was an icky conversation, and an uncomfortable thing to talk about until my dad was reaching the end of his journey. It made him feel better to pick the music at his services and readings and to say what he wanted.

For that second you have more control over something none of us has control over. You can say what you want, whether you want to be in hospice, whether you want heroic measures, the person gets the right to choose and I believe that should be part of every conversation.

Under Medicaid waiver requirements your required to discuss this part of the plan.

What I have showed you over the last bunch of times we have spoken together and today is not supported decision-making traces align their life from birth to pre-k all the way through end-of-life planning.

Supported decision-making is the thing that brings us together. That brings supports and services together. Consider this: We all basically plan the same way. We all figure out what we want, figure out what is stopping us from getting there and figure out how to get around it or through the barrier.

We do the same thing with people with disabilities. We can go through and identify that person and help them identify his or her goals, financial goals, educational goals, employment goals and independent living goals. And say okay those are the goals what is in your way? What do you need to get through to get there? And then you ask who can help?

Who are the areas? What are the agencies that can help? I showed you 4-5 different ways. I assure you more throughout our time together. Once you figure out who is going to do what and how they are going to do it you write it down and make it part of their plans. You get the culture Coordinated Support Model going so everyone knows what everyone else is doing so they can support each other and not cancel each other out.

That sounds easy but sometimes it is not. When we talk about education, I mentioned what I call the tyranny of boring goals. I think there is nowhere where the tyranny of boring goals is more than in planning for life.

We hear the same types of goals over and over again and they fail over and over again because no one cares. I have seen on so many independent living plans things like Jonathan will pay attention to and improve his personal hygiene. Or Jonathan will take better care of his home to make sure it is clean, eat healthy and do his laundry.

To which I say, who cares. If I don't do those things, who cares? If I'm not interested in what I'm doing, if I don't have a reason to do things what do I care if I'm clean or not? What do I care about these goals?

I know many of these goals are required, independent living goals are required to be part of so many plans but they are boring. They don't touch on anything we do.

Here is why I have learned this is boring. It goes like this. I know we are in the middle of the pandemic so humor me when I say this, when was the last time you were at a party and you talked to anyone about your life goals and objectives in those words? When was the last time you talked about your supports and services in those words?

We have disability issues that are so regimented that we are talking about goals, objectives, support services and providers. That is boring and frankly demeaning. I never want to talk about my goals and objectives and supports and services because that implies someone has to do something for me.

You know what temporarily able-bodied people talk about at parties? They talk about their dreams. Dreams have become a dirty word for people with disabilities because sometimes dreams are not achievable in people with disabilities who are told not to dream because of a dream they will get their hopes up and not get what they want. That is where the mistake is made.

Our dreams are incredibly important. Consider your dreams. That is what you talk to people about. Your dream life, vacation, job, car, boat. Because our dreams, even when they are unachievable, teach us about ourselves and teach other people about what we want. We choose our friends because they have similar dreams.

Dreams are about values, dreams are about who we are inside. Dreams make us and shape us.

When I was 18 if you asked me what my dreams were I had two. I want to play left field for the Yankees and rhythm guitarist for the Stones. I am never going to be either of those things. Should I be ashamed of them and not talk about them? Of course not. I still want to play left field for the Yankees. I still want to get up on stage with the Stones but I know I will not do it. You know what it tells you about me?

Consider what the dreams tell you about me. They tell you I am competitive, that I want to be active. That I want to stay physically fit. That I want to be part of the team moving in the same direction. That I like to be the center of attention. That I like to be informative and entertaining and realize I found the perfect job.

I found the perfect career. Trial lawyer. Public speaker. I found the exact job that is consistent with my dreams. It doesn't matter that I will never play left field for the Yankees. I get to be active and competitive every single day. It does not matter I will never be on stage playing guitar. I stink at it anyway. What matters is I can talk to people. I can talk to you, inform and entertain.

So my dreams shaped me. What we need to do is empower people with disabilities to dream and build supports and services around them.

I have talked around this country about a thing I call Dream-inspired Planning and that is where I want to finish up this culture of coordinated support idea because it is all about it. Three steps.

We encourage the person to dream, identify and communicate his/her dream. I have lectured and worked with high school students. Usually what they called the challengers class. The ones that are most likely to drop out. We do an exercise called dream boarding. Nothing magic about it. Go to Pinterest and type in interest board. We give these kids a piece of cardboard and we put out on a table a ton of magazines, pens, pencils, papers, glue, scissors.

After that we talk about Self-Determination why they should be taking control I say you have an hour I want you to grab any newspaper you want, any magazine or any pen, paper or marker and put on the board, don't think. Put on the board the things that matter to you. The things that represent your vision for yourself. The things you dream about.

Once they are done, we do a process called digging. After you dream you dig. Dig means getting down to the values. What did the dreams mean? Do they represent about that person? Because again those dreams may be unachievable just like yours are what they mean something about the person. Then we can develop goals, objectives, supports and services that are consistent with those values that move that person in a direction consistent with his or her dreams and values so they matter.

Here is a story. I worked with the young woman named Ellie. When asked what her dream was Ellie said she wanted to be a veterinary surgeon, in those words. Ellie was not going to be a veterinary surgeon. She will not be able to pass the course work. She had intellectual disability she would not be able to qualify for class.

Instead of saying you can never be a veterinary surgeon pick another dream we asked why is that important to you? What about being a legendary surgeon is so important. She told a story about her dog who had cancer. She went to the veterinary surgeon because the dog had a tumor. They were great. The surgeon came out and explained what they were going to do. They loved on the dog. They kept giving updates on the dog. They would call them and say how they are doing.

They let them come and look at the dog. At the end the dog was okay. The dog went home wearing a bandanna and everyone was happy. She said I want to do for dogs and I want to do for people what a veterinary surgeon and the people did there for us. She is now working as a veterinary technician. She works in an office. And walks the dogs, talks to the family she is their ambassador. She is doing something that is consistent with their values and dreams.

Here's the important part. Remember the boring goals? Now, they matter. You can say you have to watch her hiding. If your hands are dirty and you pet the dog it can get an infection and died. That is the opposite of your dream. Ellie you have to keep your clothes clean. If you don't keep your clothes clean dirt can get in an open wound and impact and hurt the dog and that is the opposite of a dream.

Now the dreams matter they are connected to what she wants. They matter. When things are connected to what we want we can build on that. We want to achieve them. The goals are not boring any more. Now they are active in their personal goals.

On the left is Morgan from Ohio and Stephen from Florida on the right. We did dream exercises and it shows the different types of dream boards. We just say go nuts about whatever you want on it. Morgan writes a lot and when she held up her dream she said I can do so much with this board. She said I want to cook an amazing people. It says I love people and I love to be creative I want to see new places and I love art.

Last I heard she was working as a docent in a museum where she met people with similar interest. Where she got to see great works of art and be creative. That is how you make friends.

We make friends with similar interests. Sometimes I get people that the board says they want to be a professional football player. I have no idea if you will be a professional football player or professional singer but I know there are chances for you to play football and chances for singing and if you do that you will find people who also like to sing and also like football and that is how we become part of our communities by getting out of our houses and doing things and meeting people.

Stephen did differently. He made pictures that said the things he is into. He is all about healthcare. He sees himself helpful. He wants to work in healthcare. He wants to help people be healthy. He wanted to be an EMT. On the back of his board you can see he wrote a bunch of notes about himself that he can take to the planning meetings. That is another thing we tell people to do is take your dream board to your planning meetings.

You take it right to the IEP meeting right to the waiver meeting and you put on the table and you say this is who I am and this is what I want, how are we going to get there? That is what he does in the build services and supports consistent with that dream.

And it works. Remember I promise no hippie trippy vaporware. Processes like these work. Project renew has been done around the country. Not as specific as the culture of coordinated Support Model it's all based on Self-Determination. Students said their educational goals and they set the process to reach them and there is coordination around education, employment and independent living.

Focusing on those things, focusing on bringing those things together the very first invented the program and this is based also on the students most likely to drop out, the ones most at risk.

One year of doing project renew 99% find work, 70% keep their jobs. 83% found employment. 75% were enrolled in postsecondary education. They were building their self determination. Project Renew is all about Self-Determination and we know Self-Determination is what leads to education, employment and independent living.

I have made culturally subordinated projects in several states. In Ohio in two counties we begin a process called the successful transition project. It is a collaboration between school, the state VR agency and an DD waiver provider. They were going to identify students at the most risk of guardianship and they would work together to put supports in place no more silos in those counties. Plans with common goals and objectives figuring out like I said who was in the best position to do what?

So teachers teach, counselors in vocational rehab and DD waiver does independent living. They wrote them up in journals.

We had one in Mansfield High School in Ohio who talked about two teachers who were part of this process that tears in their eyes because the students had never participated before.

Teachers are dying for students to take a lead role. Teachers hate the regimented nature of the IEP process.

I can tell you that spoiler alert they want passion, they want involvement.

So hearing about dreams help them revamp IEPs around the streams.

Case managers talked about learning about what people wanted in the community. In one of them a kid put on the dream board she wanted to work at Starbucks. Her parents had no idea she wanted to work at Starbucks. But learning just that simple thing allowed them to put supports and services in place that would help that young lady learn customer service.

Learn independence to work with people and she is working at Starbucks. My personal favorite. People who use the dream boards in IEP meetings. This one talked about a young woman who made her dream and said she wanted to be a fashion designer. And God bless that school, they ran with that dream. They made fashion design the basis for all of her goals.

Like if you want to be a fashion designer you have to write your ads. You have to write ad copy which became English and writing goals of her grammar, literacy, reading and writing now connected to her dream of being a fashion designer. She's going to be a fashion designer she has to budget and pay taxes. There is her math goals. Addition, subtraction, division how much money do you have and how much money can you spend?

Instead of memorizing multiplication tables we can figure out what we have to pay for rent or what we have to pay employees with phantom figures give her opportunities to learn that way.

Other dreams she came out about owning a car and making money they were able to weave into the IEP so the goals and objectives you have to have anyway, you know, English, math and science related to her dream and now they mattered. And now they mattered to her.

She is way more likely to follow up on them. I did another program in Vermont where we did the culture of coordinated support. A school, VR and DD waiver provider. The students made dream boards. They are all at high risk of guardianship. After year and none of them went in. They made dream boards. The agencies work together. One meeting, not three. After a year that like I said no one went into guardianship. After year we surveyed everyone parents, students, teachers, counselors.

Look what we found. 100% of people said it improved the supports for students. 93% said there were more supports available now. A hundred percent said it was better help identify student needs. 73% said it was easier so it is easier and results in more and better supports and it's already legally required like I told you, why are we not doing it?

This is a way we can do things. This is a way we can change but we have to start somewhere.

I want to end where I started. That we do not get anywhere in this we recognize, respect and protect everyone's right to make choices. The right to make choices is the most fundamental one we had. If I've taught nothing over the five sessions, I hope you learn that Joyce makes us who we are. If we start from a place we all have that rights, we all should have the right to make choices to the maximum of our abilities then we can make changes.

When you demand changes and this will require US, parents, people and advocates to demand changes and say we need to not do things stupidly, you need to collaborate. You will get what I called a finger wag. I get them across the country were some administrators says no, we have a way of doing things. You're asking us to change our ways. You're asking us to change the way things have always been.

When they say that to you, and they will. I ask you to tell them what I tell them yes, I am. I am asking you to change the way things have always been. Because every time we have ever done things right in this country every smart strong and good decision we have made every advance we have made has fundamentally changed the way things have always been.

Consider 1773 13 American colonies always had been the possession of Great Britain, we changed it. 1863 where I’m sitting right now in Virginia some people thought they could own other people. We changed it.

In 1918 half of the population was not allowed to vote. In 1963 a huge segment of the population was not allowed to use water fountains or sit at the counter because of the color of their skin. We changed all those things. Every time we came together and made a fundamental change and we are better, stronger and smarter as a people because of it. Even though it is hard.

Change is hard. There have been wars fought over change. There has been social upheaval over change. When you're asking for fundamental change like a change of 1500 years of culture that says people with disabilities can't do things and should be allowed to do things it is hard. When you empower someone to make choices when you encourage someone to make choices, when you use support decision-making you know what will happen?

People will make bad decisions. We all do. Everyone makes mistakes and I guarantee you someone who doesn't you support will get hurt physically and emotionally. They will get taken advantage of. I get taken advantage of and so does everyone else.

Bad things happen but when they do culture comes running at you and fingers will wag again. They will say see you made us change. If that person was in guardianship, they would be just fine and remind them that there is no science to support that.

When that happens, when it is hard that is when you have got to recommit to those commandments of supported decision-making that everyone has the right to make choices because it is hard. I'm not telling you anything you don't already know. If you're a parent or an advocate you already know it is hard but here's the thing.

Did any professional advocates, attorneys, no one got in this field because it is easy. As a parent you did not ask for it to be easy you were given it and you fought your way through it. Great quote on your screen for my favorite author. No one ever promised was going to be easy. The purpose of life is not making things easy. The purpose of life is not easy. The purpose of life is to choose to act upon our choices. When we do that when we protect, respect support power and choice,

we are not measured by who we are at the end of the day. We are not measured by the people we are at the end. We are measured by three things. Daring, effort and results. Those are the three things every parent, advocate and person with the disability needs now and forever.

You have to be bold, you have to work hard and you have to be ready to get up because you will be knocked down. That is the test. Your measured by how well you get up. Not what happens to knock you down. If we do that, if we are daring and if we work hard and we get up every time we are knocked down we change the world.

After 10 hours of hearing me talk, I will end with the cliché. Change the world. Changing the world is the most important thing we can do and it is something that you do every time you empower someone. Every time you break the mold. Every time you change the culture. Every time you help one person because the world changes one person at a time.

That is what we do. When you empower someone who would not have had choices to have choices you have changed that person's world. But just as importantly changed the world of everyone who came after that person because it is easier the second time.

Jenny Hatch's trial took a year and six days in court. The next one I did Ryan King took a day. I've had cases that have not gone to court because everyone has agreed the person can do it. Point being, do it once and it gets easier.

What we are aiming for is a different world. A world where frankly people like me are not talking about Supported Decision Making. It is time to start using the phrase. We should not be talking about Supported Decision Making for people with disabilities. We should be talking about life and making choices.

Someday we are going to. We are not going to talk about Supported Decision Making. We will talk about people. People who make their own choices giving and getting the support we all need. We do that then everything changes.

If you buy into the things you have heard me say. If you believe in the things you have heard me say that we can change the world.

Maybe it is your child. Maybe it is someone you represent or maybe it is someone you know. You can change that world and everyone that comes after it. If you buy in let's do it and if you don't buy in my fondest wish for you is that you die suddenly. That is not a joke. My fondest wish is for you to die suddenly because if you do not, if you are not lucky enough to die suddenly guess what you will be on that?

You will be old. You are going to be disabled or in the system or need services and tell me what kind of services do you want? Do you want ones that build you up, that support you, that believe in you, that empower you or do you want 1500 years of culture to come crashing down on you? I think I know the answer.

If we make that commitment, we can change the world and I would love to do it with you. Please remember my email is on your screen. You can reach me anytime.

It has been my absolute honor to be with you over the five sessions and I would love to answer any questions. I will stay as long as you want.

MORNA MURRAY: Wow! I just want to say every session has built upon the last and that was something. I will say a couple things because if everyone is as wowed as me they are gathering their thoughts and questions. I always write down sayings of yours that I like in particular.

Tonight it is the ultimate. "Yes, I am trying to change the way things have always been done." Yes, yes I love it.

JONATHAN MARTINIS: You can also use damn straight. I've used that one too.

MORNA MURRAY: Let's open it up in the chat box or just raise your hand, turn on your camera, turn off your mute.

QUESTION FROM AUDIENCE: This is John Susa again. Thank you for the great presentation. I have a couple related questions mostly from my life experience.

My youngest son is now 45 years old. I have a history and experience with special education that is pretty dated. I am loving to hear about student led IEP is and I want to ask you is that a best practice or is that legally required?

It is legally required how soon is it required in terms of where a student is in school?

JONATHAN MARTINIS: Best practice in evidence-based. There are studies where students who lead their IEP meetings do better in school and out of school. Given that IEP meetings by definition are required to focus on the student's unique skills and interests my advice to every parent and my advice to every school is to implement the student led IEP.

My advice to every parent and student advocate is to advocate for it. Nowhere does it say thou shalt use the student led IEP but the Department of Education has endorsed it and that's good enough for me.

QUESTION FROM AUDIENCE: The reason I'm asking, I don't want to take too much time but 30 years ago we asked our school department to make sure that our son who then was 15 and has multiple disabilities that he should attend his IEP meeting and the response was "What!" Whoever heard of such a thing. It is okay if you bring a picture of him but no you cannot bring him in.

We insisted and they relented. And then we asked even more which was we went a couple of his regular classroom peers to be in the IEP.

And I got to tell you it was a terrific thing that happened but of course, as you probably know, it only happened for us.

I am really interested in engaging somebody in the conversation about how do we change that from a best practice to a requirement?

JONATHAN MARTINIS: First of all, good for you that is phenomenal advocacy. Unfortunately, your experience continues. I have a good friend in New Jersey who has a daughter in high school that just attended her first IEP meeting because no one ever suggested it.

People actually discouraged it. I recommend that you show up to the IEP meeting with your kid. At three years old if the child cannot stay for more than three minutes, so be it. But to me it is so important that the student understand this is your team. That is the first step in Self-Determination. Understanding something is yours. Understanding things do not happen to you, that you do things.

To me it is day one. The best time to start is today. If your child is 15, start today. If your child is three, start today. The school, in my opinion, cannot legally refuse to let the student be part of his or her IEP meeting. I don't see how you can form an IEP without based on the student's skills and interests without asking about them.

QUESTION FROM AUDIENCE: That particular IEP resulted in an idea coming from both Mark and his peers that has been one of the hallmark identifiers of him. Mark loves the weather.

One of his fellow students said why doesn't Mark give a weather report on the PA system every morning during the announcements? We cannot get every day but we got it once a week and when Mark is now at age 45 out in the community by school kids he went to school with the first think they will say is Mark I remember you. You used to get the weather.

JONATHAN MARTINIS: That is what integration is. It is finding what someone is interested in and then building around it.

Pardon the sermon but disability services are just ass backwards. They look at what people can do. They start with what you can do. They find out all of your limitations and they start taking off the things that means real life. Instead of saying here are things you do well, here are things you are interested in and build around them.

I stink at math. I am terrible at math. But no one has ever said to me because you stink? Here is a bunch of things you cannot do. Instead I have found a career where I do not have to do math. I found what I did well and used it to get around the things I don't. That is what planning should be. Your son does the weather well.

It matters. He was more engaged in school because of it so well done, sir. Thank you. I see a hand.

QUESTION FROM AUDIENCE: First of all, thank you so much for this wonderful series to you and everyone who participated for disability rights doing it. It is just amazing.

My question to you is what is the best language to use to get a young adult with medical needs to write a power of attorney just at least in medical. The person understands it and has it on a napkin but does not want to do a legal document.

JONATHAN MARTINIS: I am a big believer in power of attorney but if you're talking about a document that gives someone else power to make decisions or something that gives someone the ability to support that person?

QUESTION FROM AUDIENCE: I am looking at someone just to support like when the person cannot make decisions because of ICU or something like that.

JONATHAN MARTINIS: The first thing –

QUESTION FROM AUDIENCE: Like I said the person has serious medical issues otherwise they do not need it. It is a medical component when they are unable to make the decisions because they are unable to speak.

JONATHAN MARTINIS: The first thing I would consider is a supported decision-making agreement to make sure the person can have a supporter with him whenever going to the doctor.

Rhode Island is one of the states that has a form for that. Is pretty straightforward. With regard to the power of attorney, I am a big fan of simpler is better. I am not a Rhode Island attorney so I will cover my butt and say consult a Rhode Island attorney and there are several on this call from Disability Rights but I think one of the things you can do is go very simple.

When I'm in the hospital and unable to make the decisions I want my mom, sister, aunt, whoever to make decisions for me about my health.

I would recommend including some parameters for those decisions what that person believes in.

I want this, I want that. I don't want you to make this decision. That way you are very clear what is he does and doesn't want and when the power comes about. It is also called a springing power of attorney because it springs into condition when the person needs it and it springs back when he doesn't.

I would recommend touching base as a start with Disability Rights Rhode Island and I'm happy to talk with you off-line if you would like but again at the risk of sounding like I am blowing smoke, I am not. Disability Rights Rhode Island has very good supports and services on this area.

I am putting my email again in the chat box inside please feel free to reach out to me. I would love to talk with you.

Sometimes the questions pop up later and that is fine. Send them to me in an email. I will answer. Find someone who can.

I think the most important thing we can do is talk together. Someone out there has been through something that you have been through. The hardest part of being a person with a disability or the parent of a person with disability is in general the isolation. You feel like this is only happening to you. Find your people and there are people who have experienced it, have advocated around it and come up with solutions for it.

We can be our own connectors. Support is not just for people with disabilities it is for everyone around them and we all use it. While I was saying that I saw a note that a son attends high school and has been leading IEPs pre-COVID since sophomore year. That to me is so important. It is just the involvement.

Never mind that the science shows it's better but people need to take that lead role in life. Again sophomore year is transition planning time. It’s planning for the rest of your life and the rest of your life you will have to make decisions and you might as well practice it and the student led IEP is a great way to do that.

QUESTION FROM AUDIENCE: This is Heidi speaking I want to say I wish that we had a million of you. I wish you could clone yourself. I have the utmost respect for you. And I thank you so much for all you have given and I will be reaching out to you in the future. I hope you come to Rhode Island in the future.

One of the main points I want to make is the things that you suggest doing for people with disabilities. I myself am legally blind, severely disabled and have cerebral palsy but one of the points I want to make is the dream boarding and things like that or tailoring the education to a person's goals. That is useful for every single student in the entire school.

And if you start a goal for a person with a disability other students may have similar goals and it may enhance everybody's educational experience and everybody's friendship experience. So bear in mind that even though this is directed toward disabilities it is common sense, it is enriching and it helps all people. And I thank you for bringing up these points.

JONATHAN MARTINIS: One, you said incredibly kind things about me and I so appreciate it.

I also don't deserve it. There are plenty of people out there in Rhode Island and across the country who can do things that are amazing. It is just a question of finding your people, finding them and making the connections.

Whatever I can do I am honored to do but it takes more than me or 10 me’s it takes 10 of you, 10 of everyone on the screen saying these are the things that have to get done. If you believe in the things that I've said, tell two people just like that you are more effective than me.

Second, you are 100% right. In fact, there's an entire educational theory called IEP for all which is based around exactly what you said. Everyone's education should be based on their individual supports, individual abilities and interest. It is just not legally required.

The things I have talked about today are focused specifically for people with disabilities because they are legally required. I encourage everyone to argue for this for every single student. I completely believe in it.

The good news is for people with disabilities it is legally required and we should take advantage of that every day to make sure the services and supports are properly tailored and properly delivered.

QUESTION FROM AUDIENCE: Thank you so much, I look forward to working with you in the future. God bless and keep doing what you are doing. People are blessed to know you and have you in their corner.

JONATHAN MARTINIS: Thank you so much. Please feel free to reach out and happy to talk about it.

MORNA MURRAY: Questions or comments from anyone? I just want to point out Kate Bowden on our call who is our voting rights specialist attorney at Disability Rights Rhode Island. She is responsible for all the great material we have on the website and trainings and all kinds of information throughout the state.

Thank you, Kate. Please give Kate a call if you need any help with voting.

JONATHAN MARTINIS: Tremendous work. Again, I'm involved in some form or another in just about every state and I have not seen any protection and advocacy system with a wide range of work and resources that I've seen from Rhode Island so please take advantage of it and please vote.

QUESTION FROM AUDIENCE: Thank you so much for organizing this and getting it recorded and making it available.

It has occurred to me as I have been watching that I wish I had had the ability to bring my cell phone into a meeting and when somebody that I was having a problem with I would just say here learn something and run a little segment. I want to make sure that when you put the stuff electronically up and available make sure it is compatible with mobile devices like cell phones and iPads.

I can see somebody flipping right to it and getting right to the issue that needs to be learned by the other people in the room.

MORNA MURRAY: Thank you, John. That is a great idea and we will do that. I should acknowledge Bruce Conklin who is behind the scenes running everything that needs to be run so that this goes smoothly. I'm sure he will figure that out.

He just mentioned it is linked through the YouTube page.

If there are no other questions and Jonathan I have a feeling there will be lots of people getting in touch with you at various points it is a bittersweet feeling to close out the webinar although I am sure we will be working together again in some capacity in Rhode Island.

I cannot thank you enough for what you have given us throughout this series and what we have now as a resource on our page that lives there for people to see anytime they need it.

Closing it out the way you did tonight with dreams, I want to add my personal thanks to you for having the courage and the commitment to stick with the message that we all believe in but we don't hear enough.

Which is if we work together, if we understand how connected we all are, all of us, we really can change the world.

That is why all of us are doing what we are doing.

I must admit a few things you said tonight brought me to tears and I thank you again. I just want to give people one last chance if there's anything they want to say before we sign off for now.

Okay.

JONATHAN MARTINIS: I will comment by saying thank you to each and every one of you who has come to any of these or all of these. Thank you for your commitment, thank you for your advocacy.

It has been a great start of a journey. I hope there is a lot more to come. Thank you so much Morna and everyone at Disability Rights Rhode Island.

(event ended at 7:46PM ET)