

17:48:25 Captioning Provided by:

17:48:34 Partners Interpreting

17:48:41 www.partnersinterpreting.com

17:48:47 508-699-1477

17:48:56 Disability Rights of Rhode Island Session2: Education, Employment, and Independent Living: Supported Decision-Making in Special Education with Jonathan Martinis

17:49:04 Tuesday, November 16, 2021

17:49:12 6:00PM - 8:00 PM ET

17:49:20 Communication Access Realtime Translation (CART) captioning is provided to facilitate communication accessibility. CART captioning and this realtime transcript may not be a totally verbatim recording of the proceedings.

18:02:46 >> MORNA MURRAY: I just want to welcome everyone. My name is Morna Murray. I am the Executive Director at Disability Rights Rhode Island. If you see that the name on your video is not yours but Bruce Conklin, you're not seeing things. If you clicked on his invitation to you, it then entered you into the meeting as Bruce Conklin.

18:02:50 You can change the name to your own so we know who you are.

18:02:59 I am going to go over a couple housekeeping issues and then turn it over to Jonathan.

18:03:10 The meeting tonight is going to be recorded. We have not started recording yet, but we will and it will be posted to the website for future reference.

18:03:23 We will have a transcript and we also have closed captioning tonight. The closed captioning is provided by Partners Interpreting and a transcript will be posted.

18:03:40 Everyone in the webinar has been muted. When we get to questions and answers, if you have a question that you want to put into the chat box Jonathan has graciously agreed that we can interrupt him for questions from the chat box every now and then.

18:03:53 We will unmute you or I can read your question, whichever you prefer. In terms of video, you can feel free to have your video on or off whichever is most comfortable for you.

18:03:59 And we will have time at the end of this session for questions and answers.

18:04:12 If you do not want to ask a question during the session you want to listen and wait until the end, there will be plenty of time. Jonathan has agreed to stay until everyone gets their questions answered.

18:04:31 So, for now, we will switch over to the recorded part so I need to wait for Bruce to get me that. And we are good to go.

18:04:59 With us tonight we are grateful to have Jonathan Martinis. He is the Senior Director for law and policy for the Burton Blatt Institute at Syracuse University. There he ensures the older adults have services they need to meet independent and inclusive lives.

18:05:30 In 2013 he represented Jenny Hatch in a case that was a landmark case in the United States. She wanted to make her own life choices instead of being subjected to a permanent plenary guardianship. Since that time he has led supported decision-making projects in New York, Ohio, California, Virginia, Vermont, Missouri and Kansas and now, as we see here tonight, in Rhode Island.

18:05:52 He has educated and trained tens of thousands of older adults, people with disabilities, families and professionals across the country on Supported Decision-Making theory and practice. He has written or co-written 40 publications on Supported Decision-Making including the first textbook and first theory to practice guide book on the subject.

18:06:11 On a personal note, I want to say I have known Jonathan for several years now and he is just the best advocate and practitioner in supported decision-making. We are pleased and proud to have him here with us tonight. I turn it over to him. Thank you.

18:06:20 >> JONATHAN MARTINIS: Thank you so much for the incredibly generous introduction which I have no doubt I will fail to live up to but appreciate receiving.

18:06:32 Good evening, everyone. Thank you for joining. My name is Jonathan. Today we are here to talk about Supported Decision-Making, specifically how Supported Decision-Making can be part of people's lives.

18:06:45 If you joined us for our first presentation that is what I call a why presentation, why Supported Decision-Making can be helpful. Why it can be a good thing and why we should try it.

18:06:57 This presentation and the three that will follow are all about how we can incorporate Supported Decision-Making into the supports and services people with disabilities use every day.

18:07:20 Today we are going to talk about how to incorporate Supported Decision-Making into special education supports and services. But as we begin one thing to remember I always begin my presentations with an Article of Faith. An Article of Faith is something we know is going to guide us through the rest of this presentation.

18:07:41 The Article of Faith today is this, students who have more Self-Determination skill, those who are better at making decisions, those who receive supports and services to help them make decisions are found repeatedly in study after study to be more successful as adults.

18:08:00 Students with more Self-Determination skills have been found time after time after time after time to be more likely to be successfully educated, more likely to be employed and at higher wages after graduating and more likely to live independently.

18:08:09 That is an important thing because that fits with decades of research that we have about Self-Determination in general.

18:08:30 We know that people with disabilities who exercise more Self-Determination have better lives. There is just a few of the study's findings on your screen. Remember what I told you last time, everything you hear from me is going to be backed up by either law or science.

18:08:46 I put about four studies on your screen right now that directly show how having more Self-Determination is directly related with better quality of life. A higher likelihood of being independent. Higher likelihood of being part of your community.

18:08:58 How can we get to Self-Determination? How can we get to the place where we are making more choices? That is what Self-Determination is after all. It is having more control over your life.

18:09:04 It is making more choices throughout your life. How do we get there?

18:09:19 We get there with ways that empower people to make choices. One of them is on your screen. Supported Decision-Making. This is the definition, if you remember, from last time. I don't care for it very much even though I wrote it.

18:09:28 It talks about working with friends, family members and professionals to help you understand the situations and choices you pay so you can make your decisions.

18:09:43 In other words if you need to know what supported decision-making is. and I said this on a greater Boston program just last night, it's what you do every day.

Supported decision-making is what each and every one of us does each and every day.

18:10:00 We all get help to make decisions in our life. We all seek out advice and assistance. We all do research. Think about the clichés we all use about decision-making. Make an informed choice. Get a second opinion.

18:10:11 Don't make a snap judgment. Think it over. They all mean the same thing. Get support. Don't rush. Get the help you need to make the decisions you have to make.

18:10:28 What we are finding from research, and this should not be surprising, is that people who make their own decisions using Supported Decision-Making are going to have higher levels of Self-Determination than people who don't.

18:10:43 Say people who don't make decisions because they are in a guardianship. We actually bore that out in 2021. We did a study right here in Virginia where I am where we work with young adults with intellectual and developmental disabilities.

18:10:58 We empower them to use supported decision-making. We talked to them about important decision-making plans. We said go make a plan, put your plan in place and we studied each per year.

18:11:16 What we found after a year from not interviewing them but interviewing family members and supporters is that people who use supported decision-making across the board felt more confident, more independent, were better at making decisions and actually made objectively better decisions.

18:11:29 Again bearing out the theory that has been shown in research for decades that with greater Self-Determination comes greater quality of life.

18:11:51 And that might be why Supported Decision-Making in my experience in this field has taken off and been accepted faster than anything I've ever seen. It has only been eight years as of August since Jenny Hatch became the first person to defeat the guardianship by showing she uses Supported Decision-Making.

18:12:01 Just in that time 13 states including Rhode Island and the District of Columbia have passed laws recognizing supported decision-making.

18:12:18 The US Department of Health and Human Services have funded multiple supported decision-making projects. The American Bar Association, the National Guardianship Association have called for legal and practice reforms to increase the use of Supported Decision-Making.

18:12:38 Private organizations like the Autistic Self-Advocacy Network. NAMI, The Arc, the National Disability Rights Network have all called for increasing access and increasing use of Supported Decision-Making.

18:12:44 So today we are going to talk about how to get to Self-Determination through the education system.

18:13:02 The question I have for you is outside of the home where's the first place you make decisions outside the home? School, right?

18:13:20 Schools where we have perverse personality conflicts where we have to navigate problems and make decisions. Therefore, the special education system for people with disabilities really is a primary place for us to learn about decision-making both why we should be making decisions and how to do it.

18:13:42 The law that created the special education system called the individuals with disabilities education act or IDEA. IDEA sets out what should be the special education system. What is it supposed to do?

18:13:44 If I went around this room and said what is the point of special education, you would all give me different answers.

18:14:01 What the Supreme Court has said is that schools should provide services and supports that provide students with educational benefits. That is a Supreme Court case called Rowley. It's about to turn 40 years old.

18:14:14 I know tons of lawyers who hate it because they say it does not make sense. What is an educational benefit? It's not specific enough. If I was to ask you, what is an educational benefit, again we would all have different answers.

18:14:22 If you have been involved in the system, you would talk to me about free appropriate public education or least restrictive environment.

18:14:28 You are entering the system you would talk about access to education. You would talk about mainstreaming and inclusion.

18:14:33 We would all have different discussions about what an educational benefit is.

18:14:56 Really what educational benefits truly are come out in the law. What is on your screen right now is the first section of IDEA. The very first section where Congress says what the purpose of IDEA is. The dark words at the bottom are the ones that tell the entire story of IDEA.

18:15:11 They say that schools are required, schools must provide support and services to students with disabilities for further future education, employment, and independent living.

18:15:28 That means by definition schools are required to do the things that will help students be more educated. More likely to be employed and more likely to live independently.

18:15:52 Therefore, what are the things that lead to education employment and living? Remember our Article of Faith. Straight up we know that students who are more self-determined or more likely to be employed. More likely to be independent living. Therefore, Self-Determination is the key to those three things.

18:16:13 If you come to the rest of these presentations, that is something you will hear me say again and again. Because science has proved it again and again that students and people with disabilities in general that are more self-determined are more likely to be educated, more likely to work and more likely to live independently.

18:16:31 Therefore when IDEA says the whole point of special education is to prepare students for education, employment and independent living what is really saying, according to study after study after study, is that the point of special education is Self-Determination.

18:16:42 That helping students be self-determined should be a best practice. That schools should be working with students to give them more opportunities to make decisions.

18:16:56 More opportunities to solve problems. More control in their education. Why? Because light control is what Self-Determination is. And Self-Determination is directly related to education, employment and independent living.

18:17:03 The thing about IDEA that we all have to realize is that it is not all that new.

18:17:23 IDEA is from 1973. It is only a generation and a half old. What is really scary is that before IDEA in the 1970s, in the early 70s and every year before that as few as 20% of students got any education.

18:17:37 There is testimony in Congress when they were passing IDEA about students with wheelchairs not being allowed in the building or not being able to get to the building or students with intellectual disabilities being told we have nothing for you and you getting nothing.

18:18:00 The lesson of IDEA the lesson of education implemented independent living the lesson of educational benefits is this: We cannot go back. We cannot risk going back because as recent as in the past as 1973 students with disabilities were not given what they needed to achieve.

18:18:13 Important adult outcomes like education, employment and independent living were not attainable because students were not provided any access to the supports and services they needed to get there.

18:18:37 Here's the scary thing. Even given the history, even given the history the sad history of students not getting any supports even given the requirements of IDEA, requiring supports and services to help people become educated, employed and live independently, we still know that the number one referral source for guardianship is schools.

18:19:00 I was part of that study in 2015. We asked guardians what was their first knowledge towards seeking guardianship? Who gave them the hand? What told them they should do this? We were expecting to hear lawyers, frankly. No, number one with a bullet across the country: Educational personnel.

18:19:22 I've heard that in state after state after state and I've been in almost all of them. Someone always says my teacher, my special education Director, an aide told me I have to get guardianship. My child is turning 17 or child is 18 and I will not be allowed to go to IEP meetings which by the way if you have heard it, it's neither legally or factually true and yet that is what we hear.

18:20:13 That guardianship is the default option. That schools do not know anything else to discuss so the concerning part is that parents are not hearing about things that

could enhance self determination. That could help students learn to solve problems. That could help students learn to achieve adult outcomes because the only thing they are being told about his guardianship. So that is where we start today. We start with the idea that special education must focus on self determination. Because if the
18:20:26 ... Self-Determination as provided by science the guardianship is not going to be a consideration unless it is truly needed. Of course, there are people who need guardians.

18:20:35 And, of course, there are people going through the school system with guardianship but we should not be discussing that until we have at least tried Self-Determination.

18:20:53 Others have been expiration of ways to help people make their own decisions. The way we do that is we start pushing Self-Determination as early as possible. I'm going to show you ways we can do it. It should be written into IEP goals as soon as possible.

18:21:03 The District of Columbia Public schools do a lot of work that includes Self-Determination and supported decision-making and pre-k.

18:21:26 I know it sounds funny. I know. I always get a laugh myself I work with their transition coordinator who states they have kids in pre-k talking about their networks and are being encouraged to have networks and it's funny because you think about a three-year-old kid on the playground getting a bunch of kids together to help him make the tough decision of cookies or crackers.

18:21:47 Doing a pro and con list of juice versus milk. It sounds like a funny thing but it's not. If you tell a three-year-old they have to make a decision and they should get help making it that it is OK to get help making a decision and a student does it than what you have done is you've begun a habit.

18:22:00 You have begun a practice. You have told the student it is OK to get help. It is OK to make your own decisions. So as the decisions get harder, as the student ages the student will have a process in place.

18:22:21 The student will have a method knowing help is OK and that is what DCPS does. They have the first written supported decision-making plan and policy in the

country. It's really quite simple. As I said, they are working with kids as young as three to introduce supported decision-making concepts.

18:22:30 They incorporate parents into that to tell parents that it's OK to encourage your student and be part of the network.

18:22:33 As the student gets older, they get a little more formal.

18:22:46 By ninth grade they talk about doing a more formal Supported Decision-Making process. Encouraging the students to identify networks of people they want to work with.

18:22:58 So that when the student turns 18 the student is ready to make decisions to the maximum of his or her ability and can, in fact, sign a supported decision-making agreement for education.

18:23:11 Remember how I said people hear all the time from educational professionals that they have to get guardianship, they have no choice? It is simply not true. If you have heard it, it's not true.

18:23:30 You have probably heard it is what is called the transfer of rights process. What IDEA says is that when students turn 17 the school is required to tell the parents that at 18 the student becomes a legal adult and has the right to make his or her own decisions.

18:23:35 It is true 18-year-olds are legal adults.

18:24:03 So what happens unfortunately is well-meaning educational professionals add a second part to that sentence. They say your child will be turning 18 next year and will be a legal adult and empowered to make his or her own decisions. And they add that means if you are not guarding you cannot come to the IEP meetings because your son or daughter is making all the decisions him or herself.

18:24:10 That is not true. If you have ever looked at any IEP meeting notice, right at the top it says you can bring whoever you want.

18:24:18 So your son or daughter even if you are not the guardian can bring you to the meeting. That is part of what DCPS is doing.

18:24:38 They are encouraging the student to create these networks to have mom or dad part of the network so it follows through. When the student turns 18, the student signs a Supported Decision-Making where the student can say going forward I want

my mother there or I want my father there and I want them to have access to these records.

18:24:56 But I'm going to make the final decisions with their support. And just like that you create a legal agreement ensuring that students can make their own decisions. That the transfer of rights does proceed but the parents aren't cut out.

18:25:12 That is an important thing. Parents should be involved throughout the IEP process from the very beginning of it and Supported Decision-Making as I'm going to show you should also be part of the process from the very beginning.

18:25:22 Let's talk about the IEP process. Once you are eligible for special education you have to have an IEP, an individualized education program.

18:25:36 I hear from parents and people across the country they hate IEP's and IEP meetings. They feel like they are getting talked at. They don't get a chance to contribute or be part of the process. I'll show you what the law requires.

18:25:53 The IEP process has several parts. The first part every year you are required to do what is called a present level of performance or PLOP. That is where you as a parent, the student, the teachers essentially compare notes.

18:26:13 What the student does well, what the student doesn't do well, what the parent or student would like to see, what they want to do going forward. These are part of an assessment process. The present level of performance as part of the IEP process and supposed to guide the school and guide the IEP team in creating goals.

18:26:30 Recognizing where the student needs help, what the student needs help doing and what kind of achievement we want the student to have. Those goals and those objectives they are called makeup the individualized education program.

18:26:43 Remember the point of IDEA is further education, employment, and independent living. So every single goal you have should have some application to those things.

18:26:46 Education, employment, and independent living.

18:26:56 I believe Self-Determination should be written into every single goal. Is how you can do it without ever using those words.

18:27:04 We can make calls that touch upon Self-Determination and supported decision-making without ever using those phrases. I promise you. Here is how.

18:27:22 I am willing to bet you guys have been victimized for been beset by boring goals. I hate boring goals. Goals that don't mean anything really to anyone. Kind of like the student will use proper grammar 75% of the time.

18:27:39 That is a goal, it is legitimate, it's measurable, it's specific and for English class I suppose. It also does not matter. Because you know what happens if the student does not use proper grammar 75% of the time? The student fails and does not meet the goal.

18:27:58 You're not learning to do anything you're not building on any skills. You are being graded on a pass/fail scale. Did you use proper grammar or not? What is that teaching and how is that directly involved in the student's life? How is that leading that student to further education, employment, or independent living?

18:28:21 Spoiler alert, it is not. It is creating an arbitrary goal or arbitrary line and telling the student clear the line or fail. What I recommend and what the Department of Education recommends is having more active goals. Having goals that mean something and have as part of it not only an expectation but a skill building part.

18:28:57 We call those "I Statements". They should be about the student, led by the student part of the student's process. Look at the boring goal. The student will use proper grammar 75% of the time. Instead of that why don't we do in active goal, a "I Statement" - I will work with my teacher to pick up subjects I am interested in and write stories using proper grammar three out of four times. It covers a specific topic.

18:29:29 It is a valid goal such as the boring one. Here's the different part. It requires the student to take action. Requires the student to do something and be partially in control of this process. I will pick stories. I will be self-determined and that is the key, remember Self-Determination in this process leads to Self-Determination and like... I is not something passive. You have a responsibility as well as the right. I will work with my teacher meaning I have to get support.

18:29:45 I have to figure out a plan to work with my teacher. You know what happens if I work with my teacher and I pick stories and I do not use proper grammar? It means I have to work with my teacher differently or pick different stories, right differently or come up with a different plan.

18:30:02 Just like that you know you see the word Self-Determination is not there. Word Supported Decision-Making is not there yet that "I Statement" is all about Self-Determination and supported decision-making because it requires the student to exercise both.

18:30:11 Get that support by working with the teacher. Use that support by doing something, by choosing those stories.

18:30:33 And if it doesn't work, come up with another way. I know that we are virtual but we are going to try something. I would love to see some hands on this one or you can use the chat box. What you see on your screen right now is a boring goal. The student will reduce the number of times she is late by 50%.

18:30:54 Again it is measurable, 50% and it goes to a specific part of the process independent living or executive functioning. Who cares. Student is late she fails and does not meet the goal. How can we write the goal as a "I Statement" in a way that builds Self-Determination and requires the use of support?

18:31:02 Anyone want to put it in the chat box or raise a hand? Never worry about being the first we can work on this together.

18:31:11 I know it is a little awkward but does anyone want to be the first one to take a chance?

18:31:25 I will do it. Consider this. Consider that this goal is boring, reactive, pass/fail. Now consider ways we can make it about the student.

18:31:44 So rather than the student will reduce the number of times she is late what about this? I will work with my parents, aide, teacher, or friends or whatever to develop a plan that will make sure I get to class on time more than half the time.

18:32:06 It is measurable, more than half. It covers a specific executive functioning area and it says the goal. But look what it does I, I have to do something. I will work with my supporters. I have to get help and develop a plan. That plan may be set an alarm.

18:32:18 It may be have someone meet me at the door or it may be make a note, whatever that plan is working what happens if it doesn't work? You make a new plan.

18:32:30 >> MORNA MURRAY: It's morning. I know you are not monitoring the chat box but we have some input here I will read off some of the suggestions, really great suggestions.

18:32:58 I will use my support system to come to school 50% or more. Kayla - I will develop a routine to get to school on time. Bethany Hogan - I will work with my teacher to develop strategies to make sure I'm on time for school 50% of the time. And then I will use my support system to come to school on time 50% or more during the school year. You know you are getting responses here.

18:33:17 >> JONATHAN MARTINIS: Those are great suggestions. What they are suggesting quite effectively is make support, make a plan. That's what life is solving problems and making plans. When we do that, we are acting proactively.

18:33:31 Even if it doesn't work, we are learning something. We are part of the process. Thank you so much for that participation. You all nailed it. That is exactly how we write a "I Statement" that gets us to Self-Determination.

18:33:39 And the whole process of making goals and objectives should and could be part of a supported decision-making process.

18:33:45 Consider what an IEP meeting is supposed to be. I know they can be tortuous.

18:34:05 I heard people say it's like eight people talking at me. But the state of the art is with the US Department of education who says we should do is what is called the student led IEP. It is what it sounds like. The student meets the process consistently with his or her abilities with age.

18:34:26 I tell parents this all the time and everyone listening get your child to his or her IEP meetings. Far too often I hear parents tell me the school says my kid does not have to come. That is your kid's team. If your kid can only stay for two minutes, so be it. That is fine.

18:34:43 But your child should know it is his or her team. The whole point of the Student Led IEP is the student leads the process. A three-year-old by and large can identify him and herself. A five-year-old can say what they like to do. A seven-year-old can say their favorite subject.

18:34:57 A nine-year-old can talk about how they like to be helped and what they like to do to get help and so on. So the point of the Student Led IEP is that the student progresses through the process in a leadership capacity.

18:35:29 I will show you some examples that might just be introducing people. It might be reading through the agenda. It might be discussing what he or she does well. Exactly the way it should be. A process like the IEP was meant to be so that the goal is as the student reaches the age of majority, as the student turns 18 as the student gets to a place where he or she has been using decision-making rights

18:35:53 They work together the way they're supposed to with the team the special education teacher, regular administration teacher, administration student, they advocate to work together. They work with everyone there so when they agree the student can sign off on the IEP. That is what the Student Led IEP is.

18:36:04 The student and team work together. The team provides the student with input, suggestions, and information. Helps the student write goals and the student decides to sign it.

18:36:10 The team supports and the student decides. Doesn't that sound just like Supported Decision-Making.

18:36:21 Special education Student Led IEP is and should be an exercise in supported decision-making because ultimately the decision has to be made to sign the IEP.

18:36:34 If the student is less than 17, a parent makes the decision but the student is part of the process. If the student is 18, then they are the age of majority and should be able to sign-up him or herself using the support of the people at the table.

18:36:41 There are so many ways for a student to add responsibilities as he or she gets older.

18:36:50 As I said younger students can generally introduce themselves and even be there as long as they can be there to know what is their team.

18:37:21 The student can talk about what he or she wants to be, with their future goal is. The student can review plans from last year. The student can talk about the present level of performance and as they get older students can do more and more things because as they understand that this is their responsibility, this is their opportunity, this

is their authority so that they are exercising more control and using more Self-Determination they can go farther and farther.

18:37:43 They can go through the agenda, they can go through parts of the IEP, they can discuss their performance, they can discuss their transition goals for the future, they can discuss what works for them. When you're discussing related services like physical therapy, occupational therapy, or speech therapy, they can discuss what works for them.

18:38:14 Here's the thing about the Student Led IEP it is not just a goal. It is not hippy trippy vaporware. We know from science, from studies, that students who lead their IEP meetings do better as adults. They're are more self-confident they better advocate themselves they're aware of their abilities and limitations and are better in accessing resources.

18:38:30 Isn't that exactly what we want for our children? Isn't this a really good definition of productive adulting? Being confident, being able to interact with your peers, doing better in your processes and knowing when, where, and how to get help.

18:38:44 That is what the student led IEP can do. I encourage every parent and student to ask for it. I want to use the Student Led IEP plan. If your school has not heard of it, Google it. Show them the US Department of Education materials.

18:39:09 Again, how do we get there? It is all wonderful sounding but how do we get to this process? First thing I recommend you do, as I said starting early, ask your school what is your policy around self determination goals and objectives? What is your policy around the Student Led IEP? Do you include self determination goals in IEPs?

18:39:31 If they look at you like you have three heads tell them they have research to do. There is one study that said the majority of teachers understand the benefits of self determination. But in their opinion the vast minority of schools actually make Supported Decision-Making and Self-Determination part of their processes.

18:39:54 You can ask for Self-Determination services and supports because you can ask for just about anything. Understand this. Under IDEA US parents have the right to request an evaluation of anything. Remember that special education the goal is preparing students for education, employment, and independent living.

18:40:11 If you believe your child has a limitation based on their disability that is keeping them or slowing them or impeding them from reaching those goals of education, employment, and independent living, you should ask for an evaluation.

18:40:35 Evaluations are covered under IDEA. I gave the citations on the screen. You can ask the school to do an evaluation to determine if your child's disability is impeding their Self-Determination. Why? Because Self-Determination is directly related to education, employment, and independent living.

18:40:57 You can write to the school and say I believe Jonathan has limitations in Self-Determination and decision-making they're keeping them for making educational progress including preparing him for independent living. I am asking you pursuant to IDEA that you conduct an evaluation of Jonathan to determine if this is so and if it is what services will help them overcome that?

18:41:12 That is an absolute request under IDEA that the school in general has two options. They can give you the evaluation or take you to do process to say they don't have to do the evaluation. Schools say taking parents to due process.

18:41:29 Someone working for the school or the IEP team with specialized knowledge or training is supposed to evaluate your student. Is supposed to review whether, for example, they have limitations due to their disability in achieving Self-Determination goals are really anything.

18:41:40 Remember evaluations can touch any topic. If you're concerned about behavior, you can request a functional behavioral assessment.

18:41:48 If you're concerned about auditory processing, you can request an auditory processing evaluation. Here we are talking about evaluations regarding Self-Determination.

18:42:01 And you know what, if the school person finds that there are limitations in Self-Determination than the IEP team has to create supports and services to overcome that problem.

18:42:21 But that is not all. If the person from the school does not find that there is limitations that you thought, then you have additional rights. You can ask for an independent educational evaluation from someone who does not work for the school.

18:42:47 again still my language. You could say Dear School thank you so much for doing the evaluation. I respectfully disagree and I believe Jonathan still has limitations in Self-Determination that are preventing him from making educational progress. Therefore, pursuant to the IDEA regulation on your screen, I request you pay for an independent educational evaluation.

18:42:57 That means they have to find someone who does not work for them and pay that person to do a next evaluation of your son or daughter's Self-Determination.

18:43:05 The IEP team must take into consideration the findings. That is the importance of evaluations.

18:43:16 It gives you a source of data. It gives you potentially multiple sources of data if you get both an evaluation and an independent educational evaluation.

18:43:42 And there are so many ways to assess Self-Determination. What is on your screen is just one of them. There is a website called I'mDetermined.org. In the I'mDetermined.org is a program of the Virginia Department of Education where they have a number of programs and supports and services around Self-Determination.

18:43:58 One of the things they have are a series of checklists you can use to evaluate Self-Determination. They have checklists that can be filled out by parents, students, and teachers at the elementary, middle school and high school level.

18:44:03 All of which are designed to look at this question. Are there limitations in Self-Determination?

18:44:06 What is on your screen is the teacher version.

18:44:18 For a student. You notice they give you a chance to rate from 0-3 with three being the highest. You are asked to answer several questions that go to Self-Determination.

18:44:31 Does my student set goals for what he or she needs? In other words, are they being proactive? Does my student ask for help when they need it? Does my student believe that working hard will help them get a good job?

18:44:45 Does my student make good choices? Here's the thing if you do that with the teacher, with the student, and with a parent you are going to be able to triangulate areas. You will be able to find areas where the student may have limitations.

18:44:59 For example, if you get a bunch of zeros the lowest possible score on does my student participate in his or her IEP meeting, you are going to know that is an area of need that should be worked on.

18:45:12 Does my student have people in his or her life that help them accomplish goals? The classic Supported Decision-Making question. Does my student have others in his or her life that help him or her accomplish goals?

18:45:23 If you are scoring low there, that is a sign you should help the student create a support network. That is a simple evaluation.

18:45:42 Remember one size does not fit all. If the school looks at you and says I don't know how to do an evaluation of self-determined evaluation. Remember I'mDetermined.org it is quick and dirty, but it's a way to get information. If the school disagrees remember you can ask for an independent educational evaluation.

18:45:51 That is what Self-Determination can do and that is why it is important to have Self-Determination goals.

18:46:07 I have been encouraging you from moment one every IEP should have Self-Determination goals whether it is a "I Statement" or anything else because we know Self-Determination is the key to education, employment, and independent living.

18:46:20 We also know that studies say that when students have Self-Determination goals in their IEP they become more self-determined. They do better in school and they do better outside of school.

18:46:48 So if you ask for Self-Determination goals and the school says we don't really do that you can say the way that this study shows we should do this because when students have goals specifically designed to enhance their Self-Determination they become more self-determined and what is Self-Determination? The key to education. Employment, and independent living. The very goals of IDEA.

18:47:05 You can write Self-Determination "I Statement" for just about anything. Here's examples on your screen. I will work with my counselor to create a budget where I have to save and spend money every month using higher amounts of money each month.

18:47:17 Boring goal. Memorize your addition and subtraction tables. Interesting goal - work with your teacher to create a budget we save this much for rent, this much has to come out for things I want to buy.

18:47:36 I can only put this much in from work. When I do that, I'm learning to do the math. I'm learning the addition subtraction and financial management and support to do it. I will work with my team to find three jobs I'm interested in.

18:47:47 Right there you working for future planning. I will develop strategies for how to stay calm and I feel like I'm getting angry. That is a self-regulatory behavior but it also involves others.

18:48:01 It is self-determined and it's supportive because it involves others. Will work with my IEP team to identify two community groups I'd like to be involved in. That's community integration and support in finding new avenues of support.

18:48:10 All of these are very typical goals written in a way that enhances Self-Determination and decision-making.

18:48:18 What does it have to do with guardianship? Last time we got together it was all about guardianship and supported decision-making.

18:48:35 Remember the story of Jenny Hatch and remember when she was examined by a psychologist that testified at her trial. What did she say? What would be beneficial to Jenny she had people around her support her and give her the assistance she needs.

18:48:42 Isn't that exactly what we have been talking about about Supported Decision-Making.

18:49:00 >> MORNA MURRAY: I hate to interrupt you, but we have conversations happening in the chat box. I will start with this: Do you have any information on the reliability and validity of these Self-Determination checklists?

18:49:12 >> JONATHAN MARTINIS: They were funded by the US Department of Education. I am not suggesting they are either necessarily scientifically valid or reliable because they are always done different ways with different people.

18:49:26 I'm not sure you can break that into an IRB type study but what they give you is a baseline of information. We are not suggesting those checklists are the one and only method.

18:49:40 When I do special Ed and I ask for Self-Determination evaluations, I get looked at like I got three heads. So where can we start? That is a good place to start. You are gathering information.

18:49:59 I'm not here to tell you they were subject to a rigorous university study. But I'm here to tell you more data is good and that creating goals around Self-Determination has been subjected to rigorous and valid scientific study and found to be absolutely beneficial.

18:50:10 >> MORNA MURRAY: Great. If the school does not want to do a Self-Determination assessment and we request an independent evaluation, who does it?

18:50:37 >> JONATHAN MARTINIS: It's actually not that process. The school has the option to either do the evaluation your request or give a good reason why not, a legal reason and usually requires taking you to due process. But independent educational evaluations are done by people who have information and expertise in the field. If you don't know one, it is on the school to find one.

18:50:51 It has to be someone who doesn't work for the school or you and the school can do research on and find one or you can look for. That is the beauty of the IEE. The school does not control who does it and the school has to pay for it.

18:51:04 >> MORNA MURRAY: Last one for now, do you have examples of how this can be addressed at school when the student has a 504 Plan versus an IEP?

18:51:25 >> JONATHAN MARTINIS: I am a huge fan of a 504 Plan. Because it is so brief it doesn't have the specific requirements IDEA does. It says students cannot be discriminated against in accessing benefits, supports, and services.

18:51:45 And you can put anything you want in a 504. If your student has a disability that is impacting his Self-Determination of 504 plan should address that. The only difference really legally speaking the only difference between 504 and special ed is due process.

18:52:02 There is no specific due process under 504. But I tell you I was involved in a case in Vermont and that is not far from you all. But the Vermont special education regulations actually encompass 504 and the things that have to be done.

18:52:10 So other school districts are aware of that. My take is you can do anything under 504 that you can do under IDEA.

18:52:24 And if the school refuses that's when it gets harder because you do not have the due process system to complain you have to file a federal complaint with the office of Civil Rights and litigate the issue.

18:52:29 That is the big difference is what's called the procedural safeguards under 504.

18:52:42 >> MORNA MURRAY: We have one more question. I know tonight is dedicated to education but are there comparable checklists for adults?

18:52:59 >> JONATHAN MARTINIS: Well, the I'm Determined checklist as you see for students but I would not have a problem using high school ones because they are again about seeking decisions and adapting them.

18:53:17 We talked last time about the Missouri Stoplight Tool which is an assessment tool for adults and decision-making. The Missouri Stoplight Tool, you can Google it. It talks about a number of adult living situations.

18:53:42 Getting to work. Making decisions about work. Managing medication. Managing relationships and anything else you can think of to put in there. It asks the person and others in the person's life to say this is something they can always do without help, greenlight. Might need some help to do well, yellow light or can't do without help, red light.

18:54:09 It's a simplistic tool mind you but it again it's a way to get information. If you see a bunch of red and yellow, it's a chance to address specific situations. There is that and the American Civil Liberties Union has an adaption of that called When Do I Want Support? You can find that when you Google ACLU supported decision-making. I think those are two good assessment tools for adults.

18:54:22 Moving on. Once again, what does this have to do these evaluations and goals how do they keep us from getting in a guardianship if we don't need a guardianship?

18:54:42 Remember with Jenny she needed to be surrounded with people who support and give assistance which sounds just like Supported Decision-Making. In fact, in Jenny's case one of my experts said this is one of the best definitions of supported decision-making even though the psychologist did not know she was talking about supported decision-making.

18:55:00 That means that this type of process having friends, family members, and professionals around the table being surrounded by people who provide assistance and support sounds just like the best practices that are already recommended.

18:55:17 Remember we've got studies that conclude that schools should be helping students improve goalsetting and problem-solving skills, having more self-efficacy and having more opportunities to use those skills.

18:55:30 Doesn't that sound like supported decision-making? Doesn't it sound like exactly like what that psychologist was talking about? And does not sound like the Student Led IEP?

18:55:47 When does guardianship happen? I struggled with this, but I finally found the study. It came to the conclusion that guardianship happens when society reaches a decision that a person can't take care of himself in a manner that is appropriate.

18:55:55 So if society believes that I cannot take care of myself in an appropriate manner it will push for me to have guardianship.

18:56:00 Now, I want you to think about all the things people need to take care of themselves.

18:56:10 All the things we need to learn about and access to learn to take care of ourselves and realize they are all available under the special education system.

18:56:20 Things like therapies and independent living supports and services, goals around functioning like creating budgets like navigating through daily life.

18:56:41 Like having therapies like occupational, physical and speech therapy. Like having behavioral assistance. Like having areas that allow you to learn to take care of yourself. Here's a spoiler that will come up two presentations from now but I want you to remember this.

18:56:51 I want you to remember the EPSDT. That stands for early and periodic screening diagnosis and treatment.

18:56:53 Here is what I will tell you about it today.

18:57:12 If a student is receiving Medicaid however, they are receiving that regular plan, through Medicaid waiver, however they are getting Medicaid and that student's school signs up to be a Medicaid provider. It is a paperwork exercise.

18:57:32 Then anything medically based in the IEP, any medically necessary support service in the IEP is covered by Medicaid. Because we have all heard about students needing supports and services. Needing specific things and not getting them.

18:57:53 Because the school says I have not seen that in school or we don't have that or that's not appropriate for the student or we think two hours is enough instead of wraparound services. Those are all codewords for we can't afford it. I like to tell students and schools they have a whole other way they can afford to pay for it.

18:58:20 Students who receive Medicaid can under a program called EPSDT that's already receiving it – they're receiving Medicaid and we will talk way more about this I promise you in two more presentations but notice that students that get Medicaid if they attend schools that do the paperwork to become Medicaid providers than anything medical in the IEP is paid for by Medicaid, not the school.

18:58:27 So just like that the schools have a way to pay for supports and services they would not otherwise paperwork.

18:58:39 That is a huge question to ask if your student is receiving Medicaid. Asked the school if they are a Medicaid provider and then show how they can become it. Google it.

18:59:14 That means all the supports and services I can help people learn to take care of themselves can be paid for through Medicaid. If the student has a disability, a learning disability, an intellectual disability, mental health disability if they are on the autism spectrum and it is causing the student to have difficulties with Self-Determination and taking care of him or herself than anything that would cover that in the IEP supports, services, assistive technologies as long as they are worded as med

18:59:18 How else can we learn to take care of ourselves?

18:59:47 That brings me to my favorite part of the special education system. Transition planning. When students turned 16, 14 in Rhode Island. At the age of 14 if you are in special education, you have the right to receive transition services. That is so important because transition services are planning for the rest of your student's life. School ends at 21 at the latest.

19:00:10 Life will hopefully go to 81 or 91. The whole purpose of transition services is to prepare the student for what comes next. In fact, the definition is on your screen

right now. The point of transition services are to help the student move from school to post-school activities.

19:00:17 Look at the bold words on the bottom including independent living, education, and employment. They are all there.

19:00:43 What is the key component to education, employment, and independent living? Self-Determination. Look what is supposed to happen. It's supposed to start at 16. In Rhode Island it starts at 14 and it goes till the student is at least 21. That means you have seven years to focus on it. Transition is about reaching the goal we all have.

19:00:48 It's about what comes next, every single person has the same goal.

19:01:11 Every kid wants to be a teen, every teen wants to be an adult, and every adult wants to live where he or she wants. Every student wants the same thing. Find the work, relationships, careers, the opportunities for long-term relationships and meaningful continued growth.

19:01:30 It means we want to be self-determined. Spoiler alert for three presentations from now. What I can tell you is this. If you don't have a disability if your student doesn't have a disability and if you do not have a disability, you are part of the system that is so affected you don't even know you're part of it.

19:01:46 For people without disabilities the system is basically linear. You progress through it from school, internships, work, college to a career or life. It's a line. There might be some bumps along the path but generally it's a line.

19:01:55 What I hear from parents and students across this country is, is no path or plan for people with disabilities because they are sent out in a hundred different directions.

19:02:07 They are in this transition. 14, 15, 16 and they have no idea anyone seems to have an idea what the supports and services are that are out there to help them.

19:02:29 They are sent to talk to one person about education, one person about employment and one person about money. But money person doesn't know employment person and maybe money person doesn't like healthcare person or maybe employment and money people are competitors but there have been turf battles.

19:02:45 The long and short of it is what I see time and time again is a fragmented system for students with disabilities. There is no process and that parents and students spend so much time trying to figure out who can help them they never actually get the help.

19:02:57 And that leads to society concluding not that the system is messed up but that the student cannot take care of him or herself leading directly to guardianship.

19:03:12 So what we need to do first and this is my spoiler alert because the last presentation we do will be all about bringing services and supports together but in the educational context what we need to do is focus on transition planning.

19:03:41 To make sure that things are there that are supposed to be there. Like I said, transition plans are supposed to facilitate movement from school to post school life. They are supposed to provide opportunities for education, employment, and independent living and what we know from the law is this is supposed to result in a plan that is based on the individual child's needs taking into account the child's strengths, preferences, and interest.

19:04:07 Sounds like Self-Determination, doesn't it? Here's the kicker. Look what it is supposed to include. Not just teaching but also services and experiences in the two ones that always get me there supposed to include transition services, include specific services to help the student achieve post school adult living objectives and acquisition of daily living skills.

19:04:32 And here is where I confess I get angry. Because schools are the number one referral source for guardianships. Just two years ago the National Council on Disability found that there is a school to guardianship pipeline that the fastest growing segment of the population going into guardianships are 18-24-year-olds with intellectual development disabilities.

19:04:51 You're more likely to be in a guardianship if you are an 18-year-old with IDD than if you are a 75-year-old. Where I get worried or angry frankly, is that school telling parents next year your child will be 18 and if you do not get guardianship you cannot come to IEP meetings.

19:05:16 When I get that, when I have someone tell me that the school said get guardianship, I always say let me have every transition IEP you have. Every IEP you

have since your child reached the age of transition whether that's 14 or 16. Looking at those bold words tell me what is a more important adult living objective in making decisions?

19:05:19 In living independently?

19:05:45 How many decisions did you make today that were important to you? how many were silly but still move you where you wanted to go? So decision-making and remember guardianships as you cannot make decisions. Well, decision-making is the daily living skill that is most important. For all of us.

19:06:26 So when I hear a parent tell me get guardianship at 18 I say give me all the transition. ...Here the Self-Determination goals. Here are the decision-making goals. Your the acquisition of decision making skills, supports and services. If I don't see that, if policy is a recommendation for guardianship at 17 I strongly recommend that parent lawyer up because I feel that school has violated IDEA.

19:06:34 I feel that school has not done what it is supposed to do given the absolute stress of independent living in IDEA.

19:06:50 Given the absolute stress on independent living in community integration and transition plan. I get angry when I hear schools are still the number one referral source for guardianship. Transition is something that you, as parents, should take very seriously.

19:07:04 You should be taking very seriously for those seven years because there are transition goals you can develop. You can be asking the school to work on transition goals for those things like community experiences. Like related services.

19:07:23 You can be working on those. You can be asking the school to help you identify long and short-term goals. To help you identify community providers. To help you identify partners. To help you create like the DC Public Schools does networks to help you with supported decision-making.

19:07:39 There's so many people that can help you do it. I hear time and time again that transition is talked about at the end of the IEP meeting. You have just gone through three hours of the IEP meeting, and you get to the transition section and the school says do you want to work or go to college?

19:07:46 If it is work, we will refer you to vocational rehabilitation. If it is college, we will send you off to a guidance counselor.

19:08:00 That is not transition. There should be a separate meeting for transition in my opinion because it's so important. And they're people you can bring to that meeting. Most importantly, my opinion is your state's vocational rehabilitation agency.

19:08:14 The entire next presentation we do is all about vocational rehabilitation. But others like service providers, a Medicaid waiver case manager, or an independent living center and if you don't know who these are we need you to learn about them.

19:08:33 I will discuss them in a later presentation, but independent living centers are specifically community-based support centers and networks that are there to help people with disabilities learn skills and get supports to live and work independently.

19:08:34 They should be at the meeting if you are working with them.

19:09:00 You can bring in agencies you are working with. You can bring in members with Disability Rights Rhode Island if you're working with them. You want as much information. Because what is the student led IEP after all and getting supports and services from people who surround you and support you and give you the assistance that you need.

19:09:14 Just like Jenny Hatch did to use Supported Decision-Making just like all the studies say help you have better achievements. You should, as part of the transition process, be asking about who the school works with.

19:09:26 Schools are already required to have what are called interagency agreements with agencies like vocational rehabilitation that says we will do this and you will do that.

19:09:36 They should be having those with other entities. I have worked in a few states to help schools set those up so that the school doesn't have to do anything.

19:09:50 If you remember the definition of transition services, it says it is a coordinated set. It should not just be the school. There should be others in the room and there should be plans that say that.

19:10:05 If we have plans we are creating an orderly system so the system is not fragmented. So there are people you can talk to at the front end rather than scribbling around when your student is 18.

19:10:24 Here's a quick primer on what I think is the most important transition partner. In Rhode Island the local vocational rehabilitation, the state agency that does what it's called vocational rehabilitation is called the office of rehabilitation services or ORS.

19:10:37 ORS as we will talk about next time, I promise you is the agency that's federally funded to help students get the supports and services they need to work.

19:11:01 But as we will discuss that covers a ton of things. In fact ORS is, too me, your most important transition partner. Right now they get a ton of money through program called the Workforce Innovation And Opportunity Act and They Are Specifically Required to provide supports and services to young adults with disabilities.

19:11:12 Federal law already requires ORS like it requires every vocational rehabilitation office to become involved in special education as early as possible.

19:11:21 I know this because I used to run the program in Virginia that advocated around that state's version of ORS.

19:11:34 That agency used to say come to us the semester before you graduate and I said that does not sound like as early as possible to me and that was until we threatened litigation that they changed the process.

19:12:17 Here is the big one if you invite ORS to an IEP meeting, it has to come. That is just flat out the law. So they are partners. They are a partner because they can provide incredible supports and services. ORS is required by law to provide every student getting a 504 plan and every student getting an IEP whether or not that student has applied for services they are required to provide all students with disabilities with preemployment transition services are what we call Pre-ETS.

19:12:36 They are an amazing opportunity. Under that ORS has to help students explore possible jobs and that means internships. They have to give counseling on transition like how you can look into colleges and vocational schools.

19:12:48 They have to give training to help students develop social skills and independent living skills and they have to provide assistance with self advocacy.

19:12:58 In other words, although skills we just talked about about supported decision-making not only does the school have to provide them, ORS has to provide them as well.

19:13:19 ORS is and should be an ally and a partner. Because remember again they have to come to IEP meetings if invited. I will spend an hour talking to you about ORS next time we are together. But know this ORS should be and could be the best partner your student has.

19:13:24 Because they can then follow the student for life helping the student work.

19:13:29 Remember this about transition. In your state you have seven years.

19:13:45 From 14 to 21, seven years, to help set up supports and services, help identify what the student needs, find apartments, have the community experiences and to develop those daily living skills like decision-making.

19:13:56 All of these the Student Led IEP, the transition planning, and the "I Statement" they are all geared to helping your student become more independent.

19:14:19 To become more self-determined. If you follow through with those you are giving your student the best chance to develop independent living skills, to become part of the community. Direct linkages to the supports they need after they need and to learn and practice decision-making and Supported Decision-Making skills.

19:14:23 That is how we close the on ramp to guardianship.

19:14:35 Because if we do these things the only people that will need to guardianships are the ones who truly need them. It will not be the default option anymore. Research backs this up.

19:15:03 There is a model, it's only one model but it's a very interesting one. It is called the self-determined learning model of instruction. SDLMI. It has been piloted and tested again and again at the University of Kansas. Under the SDLMI it is all about students doing goal setting, problem-solving, students are encouraged to take the lead role in creating their goals.

19:15:15 And to constantly assess whether they are meeting the goals. And to change course if they need to. So you are saying create a plan, monitor the plan, and make changes as you need to.

19:15:33 What we have known is just that self-determined focus has led to incredible success for students. Students using the SDLMI who are more self-determined mind you have been shown to be more successful in school and were successful out of school.

19:15:43 So again, I say as you are advocating for your school to do greater amounts of Self-Determination training, consider discussing the SDLMI.

19:16:01 There is a ton of material on it online. And what we know also in this is again a spoiler for three presentations from now, when we coordinate remember transition is supposed to be a coordinated set of supports and a coordinated set between multiple agencies.

19:16:19 I put a pilot project like that in Vermont where we worked with the school and their version of ORS and the waiver provider. We worked on developing Self-Determination goals working together so there was that more linear process and what we found out was this.

19:16:41 We did it for a year with a set of students and not one went into guardianship. And when we surveyed the students, parents, teachers, and counselors 100% said working together and focusing on Self-Determination provided better ways to identify student needs and better ways to meet them.

19:17:05 It was better at preparing students for life after high school. This is the lesson we take out of this. Self-Determination is all. We know Self-Determination is the key to education, employment, and independent living. Our job as family members and advocates is to find ways to exercise and enhance Self-Determination and Supported Decision-Making is a way to get there.

19:17:25 If we do that, we can reach each and every one of our goals. We all have the same goal, remember. Our goal is to be self-determined. Our goal is to be the causal agent in our lives. We all recognize that we all need help sometimes and that is where Supported Decision-Making comes in.

19:17:50 With that by working with, by empowering students by respecting and protecting the right to make choices we can get them the same opportunities for success and security as everyone else. With that I'm happy to answer questions. My emails on the screen.

19:18:00 I ask you to please feel free to email me with any questions. I'm happy to provide whatever support I can. With that, what questions can I answer for you?

19:18:23 >>JOHN SUSA: Hi Jonathan. This is John Susa. I am becoming a groupie of yours I hope you don't mind. I have actually two questions. The first one is about Supported Decision-Making specifically.

19:18:47 I'm constantly talking to parents who have been convinced by someone and I have a list of suspects who are told that "Oh, you know, your child's IQ is so low that he's only like a seven-year-old and certainly you would not let your seven-year-old make important decisions about blank."

19:19:00 What should parents do and say when they get told that their child's IQ is the indicator at whether their child should or should not have a guardian?

19:19:17 >> JONATHAN MARTINIS: I think IQ is a terrible measurement of decision-making. First of all, consider every IQ test you've ever taken. Think about what they are. The student goes someplace they have never been before.

19:19:30 They are meeting with someone they have never met before and they are asked to do a bunch of things they have never done before. That is not what decision-making is. Decision-making is a learned skill.

19:19:47 I tell the story of Jenny Hatch for that reason. Her measured IQ is 49. My expert, the psychologist I took her to with the hope that he would testify for us said with a 49 there is no way she can make decisions.

19:20:07 Then he thought about and said I will take her to lunch and see what I can figure out. He came back from lunch and said she makes her own decisions. She looked both ways before she crossed the street. She ordered, paid, counting her change, did not talk to strangers, she watched her hygiene and made a pleasant conversation.

19:20:24 That is what decision-making is. It is a learned set of skills that we experience. Mental age to me is offensive. There is no correlation of that by the way with anything truly scientific, number one. Number two, it is so demeaning the mental age of a seven-year-old.

19:20:44 First of all seven-year-olds, and I have two 11-year-olds, it wasn't long that I had 7 year olds. They make lots of decisions. So if a person cannot make all decisions in his or her life and having the mental age of a seven-year-old means he or she can make a few can we can build on that.

19:20:56 There are studies showing that women with intellectual disabilities even severe and profound given the opportunity to make decisions got better at it. It is a skill.

19:21:11 Given everything we know about Self-Determination we should be giving students and people with disabilities every opportunity to exercise Self-Determination and to learn how to do it. We should not give up on anyone.

19:21:16 I know you don't but to me that is what sets my hair on edge is that giving up.

19:21:23 Your 18-year-old has the mental age of a seven-year-old therefore your 18-year-old is never going to amount to anything.

19:21:27 I know most parents when they hear that they get pretty angry.

19:22:09 >>JOHN SUSA: Great. Second question is related to transition. Again, advice for parents, what should parents do when at the transition process the school says "Well, in terms of independent living and adult services we recommend that you enroll your child in the division of developmental disabilities as soon as possible, get services for them and seek residential placement?"

19:22:30 >> JONATHAN MARTINIS: That's not good enough. We will leave out the residential placement part. But the transition process is the schools ultimate responsible for ensuring their supports and services around independent living. All they are going to do is refer you out. They're not going to do their job.

19:22:52 I'm fine with bringing someone in there have to be independent living goals too me. The "I Statement" is independent living goals. It's not enough to shunt your kid off. It's good to bring vocational rehab and I have no problem with vocational rehab and the school working together dividing up the labor.

19:23:10 We'll talk about that in the last presentation but just to abdicate their responsibilities is not appropriate. I would say to the school what law or regulation gives you the right to not do what IDEA requires you to do?

19:23:16 Other questions?

19:23:36 >> MORNA MURRAY: There is a question in the chat box. What are your feelings on the person at the age of majority not being able to communicate that they need help with decision-making without being prompted to do so? Is SDM appropriate or is there another option you suggest?

19:23:56 >> JONATHAN MARTINIS: I mean maybe every person is different. I don't suggest SDM is the right path for everyone. I'm not saying you did not do this, that we have to get started on SDM and decision-making early so we avoid as much as possible that problem.

19:24:04 Supported decision-making should not be a yes or no question at 18. It should not be age of majority let's see what you can do.

19:24:21 I always tell advocates that they have to introduce supported decision-making early because if you tell a parent when your child is turning 18 you have two options this thing you never heard of and guardianship which everyone is telling you to get which one are you doing?

19:24:24 They are going to pick guardianship every time. So with every child it is the same.

19:24:38 That's why I always talk about DCPS's policy talking about taking decision-making and working with networks and be more self-determined from a young age.

19:24:51 The sign says that the earlier we start supported Self-Determination the more likely the student is going to be to recognize limitations and take the steps necessary to address them.

19:25:05 In general, when I have a student who isn't as aware of his or her limitations when I talk about is who are your go to people? We all have go to people in our lives.

19:25:21 When one of my kids has trouble in school, I go to my sister she is my go to person who is an educational professional. I have a buddy who is my go to person about all things cars. I have another one about my finances.

19:25:55 We are not saying you don't know how to make decisions and you need help we are saying go to your go-to people. Find your people. That is much less than you are unable. That is of course you can but that's why you have people. You find ways to have that discussion as early as possible. I was honored to be part of the first supported decision-making litigation in Wyoming just last week and it was about convincing the judge we have go-to people.

19:26:13 The person I was working with had entire plan that listed his go-to people and what they help with. He did not have to say I can't do it so you do it with me it was just

that's how I worded the conversation. Who are your people and what do you do with them and don't you want to do this and that with them going forward?

19:26:16 Absolutely I do. Supported Decision-Making.

19:26:20 Other questions?

19:26:44 >>QUESTION FROM AUDIENCE: I have a question actually. What do you think the correct approach should be when in some instances the barrier towards the process of the decision-making happens to be the parents?

19:26:58 And I am saying this based on my experience with working with families from different cultures.

19:27:11 They are very eager to say my kid can't make any decisions. And they are pretty hard to convince them that yes, they can if given the opportunity.

19:27:16 What do you recommend in this particular instance?

19:27:30 >> JONATHAN MARTINIS: When I work with parents, especially parents who are skeptical I always ask them what they want for their child. What do you want for your child's future? I always get some version of this answer. It's a great answer.

19:27:36 I want my child to be as happy as possible, as independent as possible, and as safe as possible.

19:27:43 I can work with that. We can talk about ways to let people be happy, safe, and independent.

19:27:55 That is what we know from Self-Determination and Supported Decision-Making and we work -- I have worked with people from cultures that have a very strong familial unit that we take care of our own.

19:28:06 And the my child can't do it comes often from the we take care of our own, we take responsibility it is our family which is a wonderful thing.

19:28:29 So I build on that. That is what family does. Family is supposed to support. Family is supposed to be there. And I bet you there has been something that child has done or said or decided even something frivolous with support but if we can break that little tiny hole in the argument that is what you do.

19:28:47 You help. How have you helped? How has that person gotten help? You start helping and that lightbulb goes on that it is not about that taking care of someone, it can often be simply supporting them and being there for them.

19:28:52 That doesn't mean the parent is out.

19:28:58 It means the parent is in always. And the child has something that will live on after the parent is gone.

19:29:16 It is a legacy, isn't it? That's how I work with it is to say your culture, your belief in taking care of your own is what's going to protect your child. It's going to work. It's going to support your child to make those decisions. That is a great starting place in my opinion.

19:29:21 Thanks so much. Other questions?

19:29:43 >> MORNA MURRAY: Anyone who wants to ask a question you can unmute yourself and go ahead.

19:30:12 >>ALLISON MARTINEZ: I have a question and it's not necessarily relating to a school aged adults I don't know if it's appropriate to bring up tonight. It's more related to the last time we met. Supporting an individual who their family member has guardianship of them.

19:30:28 The person has expressed an interest in supported living. She has expressed everything she wants in her life, what it is going to look like. The guardian has completely shot it out of the water saying it is not an option. It's never going to happen.

19:30:39 She always changes her mind. Just Debbie Downer everything. Just completely shut down the situation, the opportunity for the individual.

19:30:54 I was just curious not being too familiar with guardianship and the legalities of everything but what leg do we have to stand on as an agency to support her to continue to obtain what she wants when it contradicts with the guardian?

19:31:10 >> JONATHAN MARTINIS: It is a super dicey situation, I know. Because ultimately the Guardian has legal authority to make those decisions including signing off on a patient centered plan. I recommend two providers is the same thing I recommend to everyone.

19:31:17 What you can do is talk to the parent, talk to the guardian and advocate for the child.

19:31:45 And if you believe as a provider that that guardian is taking positions that aren't in the best interest of your client, then frankly, your responsibility is to do something about it and anyone can write to the court. Ultimately the guardian over

everything is the court. The court is supposed to receive annual reports on this person's progress.

19:31:56 Guardians are required to provide reports that the judge is supposed to review annually. I think you can write to the court and say as a provider these are my concerns.

19:32:18 I have had providers do it and I know it's dicey because the guardian made them fire you. I get it. But we are here, we are in this field to support the people we work with. I would try everything I could to convince the parents.

19:32:41 And if you are convinced it's not just a difference of opinion but actually a guardian that even for the best of intentions impeding the person you're working with accomplishing the goals of your project then yes I would ultimately one, consider referring to Disability Rights Rhode Island but also going to the court.

19:32:58 I know that is not a terribly satisfying answer. I do hope you are able to talk to them and they can see reason. I know sometimes they don't. I am involved in a case right now but that is exactly what's going on.

19:33:14 The provider wrote to the court and the provider got fired. I'm now representing another family member trying to become the guardian of this person saying I would provide appropriate supports and services will not impede this person's progress.

19:33:24 >> QUESTION FROM AUDIENCE: I've kind of asked you this question before but this past question prompted me to ask it again.

19:33:40 There are certain circumstances where the guardianship is held by two parents who are divorced and still kind of struggling with the issues that caused the divorce.

19:33:54 The end result is that their child is suffering in terms of their limitation on their Self-Determination and their choice-making.

19:34:14 Any advice about what families could do, what advocates could do in that situation? It is a little different than a provider in the sense that there's no real provider involved here other than friends in advocates.

19:34:19 What can we do about that?

19:34:26 >> JONATHAN MARTINIS: I call that relitigating the divorce and it happens more than even you know because they treat it like a custody battle.

19:34:48 >>QUESTION FROM AUDIENCE: When there is partial guardianship and people are given certain powers and there is mission creep is there anything that can be done legally to prevent that mission creep from going into other areas?

19:35:03 As far as I'm concerned, the decision about where someone lives should not also impact what people do during the day nor should the impact on their employment nor should impact on the choice of friends and relationships.

19:35:17 But it seems that often becomes the case. Is there some way to protect people from the fall out about conflict?

19:35:43 >> JONATHAN MARTINIS: Step one, write the guardianship order specifically. Studies show that over 90% of guardianships give the guardian all power. Literally all power. When the guardian is given all power, then you can decide where they live, where they go, who they see and when they work. I believe guardianships should be written tailored to the individual specifically saying what powers the guardian does and doesn't have.

19:36:38 In fact, most state laws actually require that. Two, if you are a friend or family member all you can do is try to encourage the bickering divorcees to come together for the best interest of the child and if their continuing relitigating of the divorce is putting the child at risk or impeding the progress to the child and I give you the same advice I gave earlier you tell the court. Anyone can file information with the court order protection and advocacy system asking that it be investigated as

19:37:02 it's often said guardianship is not suited for court system. There are winners and losers. So before we go to the courts, before the courts get involved it's why I talk about finding alternatives. When the courts are involved, you hope to have the parties see reason and if they won't you hope the court would do something.

19:37:07 Again, not comforting I know, but it is the reality.

19:37:10 >> QUESTION FROM AUDIENCE: Thank you.

19:37:22 >> MORNA MURRAY: Any other questions? Comments?

19:37:54 >>QUESTION FROM AUDIENCE: I don't know if this was brought up before but one we talked about IEP meetings the importance of including people who are not

always in charge like teachers are always in charge, attorneys are always in charge, parents are always in charge of bringing a friend or sibling or other people of that kind of the same level as the person that should be directing their own IEP meeting

19:38:06 I don't know if that was earlier but something I always found important. On top of that I absolutely love tonight. I feel fired up and I am energized. This is awesome. Thank you.

19:38:23 >> JONATHAN MARTINIS: Thank you for that. And two, thank you for your comment. I completely agree. Support includes supporters. The scary thing about an IEP meeting is it feels like there are all these authority sources there.

19:38:45 What we want is to make sure the student isn't ... Leaders also have people on their side. And by the way if you're a parent and you are at an IEP meeting I think you should bring someone too if only someone to take notes. You can prepare and watch you can bring whoever you want.

19:38:51 It is on the top of the notice for the IEP meeting. I suggest you take advantage of that.

19:39:18 >> MORNA MURRAY: You're getting a lot of thank you's. Thank you for the amazing presentation in the chat box, Jonathan.

19:39:34 >> JONATHAN MARTINIS: Thank you all for coming. Just as a quick sign posting the next presentation we will be talking about vocational rehabilitation. After that we will talk about supports and services around what I probably call healthcare and life planning.

19:39:47 We will talk about money management and the last presentation is how to bring all the things we talked about together and I will show you how it all links. And I am looking forward to working with you on all of that.

19:40:06 >> MORNA MURRAY: We are too. Jonathan, thank you again for a fabulous session. So informative and so inspiring and positive. So practical. Our next session will be Thursday, December 2 at 6 p.m.

19:40:16 Two weeks and two days from today we shall be here and we look forward to seeing all of you here as well.

19:40:38 >>QUESTION FROM AUDIENCE: I am a little slow on the draw. Jonathan, you did mention in the upcoming presentations anything specifically about housing if you could shoehorn some examples of

19:40:45 living arrangements into some of those, it would be very helpful.

19:41:02 >> MORNA MURRAY: Thanks again. Goodnight, everyone.

(event ended at 7:41PM ET)