

RICK GUIDOTTI: Thank you, everybody. That was amazing.

I have goose bumps.

I'm so excited to see. I want to thank the WITH foundation, to help us create this FRAME film on Supported Decision Making. We really need to create more opportunities to healthcare providers in training, there is such a thing as supported decision making and what that looks like.

WITH Foundation, thank you so much for your support. And incredible actors and super stars of this film, using their lives and sharing their experiences in Supported Decision Making. Reach out to each one of you.

Start with you, Oscar. You're kind -- you kind of put it all together for us in the beginning.

First of all, what did you think of the film? And how did you look?

>> OSCAR SEGAL: I really looked great. I enjoyed the film a lot.

Next step for Supported Decision Making, talking to legislators, plan to talk to legislators. Getting this new law in New York, Virginia, Illinois, Oregon, and Washington, D.C. Not New York, Virginia, Illinois, Oregon, Washington, D.C., I will have those lobby days. I will still go to other parts up state, speak to legislators.

I'm meeting with coach, merry elia, I'm going to get paid \$50 an hour.

>> RICK GUIDOTTI: Great. Please keep in mind, once we can open up, Omicron variant is gone, open up our gallery, back up and open, we love to have a whole afternoon of supported decision making, not only a panelist, but also an advocate, some of our other great friends in Supported Decision Making venue, u renea, hey, Ray, what did you think? Was it okay? You're muted, ray, I can't hear you.

>> RAY SEGAL: It was fabulous.

>> RICK GUIDOTTI: You were amazing.

>> RAY SEGAL: Really enjoyed it.

>> RAY SEGAL: You seemed to get all of the major points. Great to see everybody else, Trina, hi, it was really nice to see, Nelle, Christopher, nice to meet and see everybody in the film.

>> RICK GUIDOTTI: Awesome, thanks, Ray.

And Trina, how are you? What'd you think?

>> TRINA HAZELL: I think it was awesome. I really hope the message gets across to a lot of great medical students and medical professionals who's going to be watching.

>> RICK GUIDOTTI: Nelle, again, it's really kind of creating opportunity to healthcare professionals, decision making is a thing. Website, under programs, we'll add links for more information. This is only a ten-12 minute film.

It's really important that we introduce it. Add current links.

Find out Supported Decision Making in their area.

We'll have all those links on the website.  
Once we add this and that will be in the next day or so.

You'll have access to really important links to move further with this.

Dr. Nelle, what did you think? Any comments? Thank you, Trina.

>> NELLE RICHARDSON: Oh, my gosh, I'm in tears. Wow, I think it was really fabulous.

You did a great job, Rick, thank you so much.

But the bottom line is, as Trina says, I really hope message is set forth. And I really hope parents and the persons who do need this service.

Does come on board.

It's a really important message being sent across, that voice, you know, now that they've seen that others have done it and are doing well. I just hope they will also join knowing they will also -- it will also benefit them.

Really grateful for the message.

You did an awesome job.

>> RICK GUIDOTTI: So did you, you're extraordinary.

00:28:36.506 --> 00:28:38.757

Grateful to our beautiful film crew from Diplodocus.

Wonderful team to collaborate.

Great friends of ours

Start FRAME film, early Library. FRAME films online film library, access on our website.

Thanks, Dr. Nelle.

Christopher, and what you thought, and Siert

Siert, I did see on captioning on the film, we will create.

00:29:08.206 --> 00:29:12.957

We'll correct that immediately.

00:29:12.957 --> 00:29:19.207

Thank you. So Christopher, and Siert.

00:29:19.207 --> 00:29:22.957

>> PARTICIPANT: I get that spelling all the time. So I don't care, really.

00:29:22.957 --> 00:29:32.157

>> RICK GUIDOTTI: (Chuckling) okay.

00:29:32.157 --> 00:29:36.558

>> I did like the film. I don't really get impressed by that type of film often, but that was very impressive.

00:29:36.558 --> 00:29:40.208

>> RICK GUIDOTTI: Wonderful. Thank you so much.

00:29:40.208 --> 00:29:41.657

>> CHRISTOPHER KIEWIET: You did aigate .

00:29:41.657 --> 00:29:43.757

You did a great job.

00:29:43.757 --> 00:29:48.307

Key points, and starting from the top.

00:29:48.307 --> 00:29:54.307

And having the medical field, and professions understand.

00:29:54.307 --> 00:30:01.857

All the way down, but just to make sure that everybody stays individuals.

00:30:01.857 --> 00:30:05.456

I think this really shows everyone as an individual and special people that we all are.

00:30:05.456 --> 00:30:17.507

And just fantastic job, great job, Rick.

00:30:17.507 --> 00:30:36.408

>> RICK GUIDOTTI: I want to thank you, Christopher, so much, making sure it's important that the hear healthcare providers and team really ask the right questions.

00:30:36.408 --> 00:30:51.906

>> LIZ GROSSMAN: Question from our audience, from gym Clark, some parents are worried unspoerd Supported Decision Making, they fear it will make people less safe compared to guardianship. Special parents who chose to not to pursue guardianship?

00:30:51.906 --> 00:30:58.708

>> CHRISTOPHER KIEWIET: We actually did not wish to pursue guardianship, guardianship can be something that can be very difficult to undo, and that can be detrimental to our son's future, we believe.

00:30:58.708 --> 00:31:11.808

Having Seertinvolved on the level he is and to extents he will be.

00:31:11.808 --> 00:31:20.408

Does, does more than just give himself a voice, it also provides a, um, a level of reresponsibility and a means of being able to forward think.

00:31:20.408 --> 00:31:24.407

Where you're not going to find yourself in a situation that could potentially become more detrimental.

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Than what it was originally maybe kind och designed to be.

00:31:26.056 --> 00:31:32.808

It really gives him.

00:31:32.808 --> 00:31:39.558

And gives us parents and family that flexibility where he is constantly involved.

00:31:39.558 --> 00:31:42.407

And he maintains that individualism that he deserves.

00:31:42.407 --> 00:31:43.807

>> RICK GUIDOTTI: Beautiful.

00:31:43.807 --> 00:31:52.858

All right.

00:31:52.858 --> 00:31:56.908

>> LIZ GROSSMAN: Another question, ever opportunity for both to have guardianship and Supported Decision Making?

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>> RAY SEGAL: That's actually our situation.

00:32:01.708 --> 00:32:06.257

Oscar's situation and our family's situation.

00:32:06.257 --> 00:32:12.158

Supported Decision Making didn't actually exist when Oscar turned 18.

00:32:12.158 --> 00:32:24.258

And we went through that process. And now, we're several years out into it.

00:32:24.258 --> 00:32:25.557

I think you can tell from the film, we're very much in favor of the philosophy and underlying principles that are at work.

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In Supported Decision Making.

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But it's a conversation.

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I think the issue, Jim, who asked the question out there, not necessarily an either or.

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You know, idea here is you're doing what's best for the person.

00:32:53.958 --> 00:33:01.059

And just the idea of spreading responsibility among a whole group of people seems to be shgs , in a lot of ways, much better proach approach for the long rn.

00:33:01.059 --> 00:33:05.407

And gives a lot more flexibility in terms of decision making.

00:33:05.407 --> 00:33:13.407

Not really sure every situation is appropriate for Supported Decision Making.

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It's a decision the individual and their family and supporters have to come to together.

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I think Dr. Nelle, Dr. Richardson spoke really directly about that.

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About how she had to talk to her Trina's mother.

00:33:28.708 --> 00:33:41.857

It's hard for parents to make these kinds of decisions.

00:33:41.857 --> 00:33:45.258

It's [distorted audio] people -- won't be people there in the long run, government won't be there in the long run, how do we make decisions in the long-term?

00:33:45.258 --> 00:33:50.007

And more typical who.

00:33:50.007 --> 00:33:51.557

More people who participate in this, able to answer these questions.

00:33:51.557 --> 00:34:00.757

>> RICK GUIDOTTI: Beautiful.

00:34:00.757 --> 00:34:04.657

>> We have seen so much turn over in Oscar's world in terms of people working for different organizations that support him.

00:34:04.657 --> 00:34:08.457

Always my concern, how do we create consistent base?

00:34:08.457 --> 00:34:11.407

Who are these people that he knows that we don't?

00:34:11.407 --> 00:34:19.357

That always worries me.

00:34:19.357 --> 00:34:34.408

>> RAY SEGAL: Just one other thing, which is not everybody has the kind of community that Oscar does.

00:34:34.408 --> 00:34:38.858

There are a lot of people, a lot of people with disabilities are very isolated, they don't have a wide group of people they know outside of the people who they're having essentially professional relationships with.

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That's an important issue that needs to be addressed.

00:34:58.206 --> 00:35:06.857

And I think addressing this issue or concern or worry about, about this -- that Jim's talking about, about, you know, not being somebody not being safe in the long run.

00:35:06.857 --> 00:35:16.006

>> RICK GUIDOTTI: Of course, making it really clear, as Nelle says in our chat, it's not one size fits all.

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And how that works for each and all of us. And how that can be tailor made of course.

00:35:18.557 --> 00:35:21.757

Liz, I saw a couple things in there.

00:35:21.757 --> 00:35:30.307

>> LIZ GROSSMAN: What makes for an ucsaysful.

00:35:30.307 --> 00:35:38.508

Successful supportive decision making team? How well do people communicate with each other?

00:35:38.508 --> 00:35:53.559

>> RICK GUIDOTTI: Trina, would you like to take that? What makes for successful Supported Decision Making team?

00:35:53.559 --> 00:36:03.706

>> TRINA HAZELL: I think what makes for good successful Supported Decision Making team is that everyone understands what you really want out of your Supported Decision Making team and what you really want out of life.

00:36:03.706 --> 00:36:10.257

And almost have the same vision as you, so they get to see you on inright path.

00:36:10.257 --> 00:36:12.257

>> RICK GUIDOTTI: Beautiful. Oscar, you have a great team around you, what makes your team successful?

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What's communication like?

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They speak to each other? Osace they.

00:36:32.757 --> 00:36:38.257

>> OSCAR SEGAL: They do. Though show these legislators, yem going to more than one capital. People want to know who I am, and all the offices when I meet officers with hunter.

00:36:38.257 --> 00:36:52.059

>> RICK GUIDOTTI: Beautiful. Thank you, Oscar. That's extraordinary.

00:36:52.059 --> 00:37:02.558

One question from Joan, for Trina specifcly, how you're using Supported Decision Making agreement today?

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>> TRINA HAZELL: Sure. One thing that I was able to accomplish using my supported decision making is that my supporters made sure they encourage me to finish college.

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And I did that.

00:37:11.357 --> 00:37:12.707

And now I'm focusing on making all my other dreams and goals come

00:37:12.707 --> 00:37:14.907

true.

00:37:14.907 --> 00:37:50.957

>> RICK GUIDOTTI: Beautiful. Gorgeous.

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I see we had a question from oddra, have Liz ask that. Our great friend Audra writes, could someone please care clar fly legal status of Supported Decision Making status in New York City or New York state, when our certain turned 18, max, told Supported Decision Making was not an option. So can someone talk about the Supported Decision Making here in New York? I think.

00:37:54.807 --> 00:38:20.958

I think -- Oscar, would you like to?

00:38:20.958 --> 00:38:32.356

>> OSCAR SEGAL: Yeah, Deborah powers, in center for support suggested, mandy, another advocate, hunter, Linda, my support broker, also with hunter and mandy too, not only with me, something Deborah suggested, she CC'd her boss, Nadie daily, Deborah thought this would be a good thing for me.

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>> RAY SEGAL: Oscar was part of a pilot program. There is no legal standing as far as I know for Supported Decision Making in New York state at this point.

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It's -- and I'm, I don't follow along. Maybe somebody else can talk about this a little bit more, about exactly where things are in the, in the, youb, you know, getting this passed into law in New York state.

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There are people who have been working on that for a while.

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Does anybody else -- maybe want -- one of our --

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>> RICK GUIDOTTI: I do see a response from our amazing Hezze who says, answer to the question about whether Supported Decision Making is available to folks in New York City. Hezze y, would you comment on why that was a bad response or why what you want us to do about that?

00:39:32.106 --> 00:39:44.456

Talking about availability of New York about Supported Decision Making, are we all feeling we have access to that?

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I baunt hang on, let Hezzybe a panelist.

00:39:48.257 --> 00:39:54.207

Let's see if we can do tat that.

00:39:54.207 --> 00:39:57.207

Oscar, you mind going on mute again.

00:39:57.207 --> 00:39:58.206  
>> OSCAR SEGAL: Okay. I'll go on mute.

00:39:58.206 --> 00:40:00.756  
>> RICK GUIDOTTI: All right.

00:40:00.756 --> 00:40:09.406  
Host and panelist.

00:40:09.406 --> 00:40:12.606  
Hezzy my friend, not sure how I can get you as panelist.

00:40:12.606 --> 00:40:14.656  
I can do it this way.

00:40:14.656 --> 00:40:16.406  
Sorry.

00:40:16.406 --> 00:40:37.106  
Okay.

00:40:37.106 --> 00:40:41.507  
All right. Sorry, Hezzy, I don't see how I can make you a panelist. Sorry, guys, there's gotta be an easier way -- Ray, you're muted.

00:40:41.507 --> 00:40:44.207  
>> RAY SEGAL: Yes, I'm back. Oh, can you hear me?

00:40:44.207 --> 00:40:45.158  
>> RICK GUIDOTTI: Yes.

00:40:45.158 --> 00:40:46.856  
Okay.

00:40:46.856 --> 00:40:52.159  
>> RAY SEGAL: Okay.

00:40:52.159 --> 00:41:18.907  
>> RICK GUIDOTTI: We can hear you now.

00:41:18.907 --> 00:41:25.408  
>> RAY SEGAL: Why don't we just read what Hezzy has to say. Unfortunate answer to that question about whether Supported Decision Making is available, so Hezzy, Kris and Joan are here from Supported Decision Making. H,.

00:41:25.408 --> 00:41:32.407

Probably very easy to do, I don't know how to make you panelist --

00:41:32.407 --> 00:41:33.857

>> RAY SEGAL: Legislation passed state senate last session and reintroduced in this session.

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>> RICK GUIDOTTI: Okay.

00:41:41.207 --> 00:42:18.207

>> RAY SEGAL: Hezzy, yeah. So, yeah. So here we are.

00:42:18.207 --> 00:42:27.607

>> RICK GUIDOTTI: So here we are. Because even if Supported Decision Making agreements do not have formal legal recognition currently in New York state, which they don't, they are still powerful documents that can change how people support and relate to each other and solve touch and solve decision-making questions together." So, true, Hezzy, value in Supported Decision Making and all these agreements and contracts together, but to create opportunity to show importance of this philosophy of Su

00:42:27.607 --> 00:42:37.008

Yes, Hezzy, I'm right there with you on that. Anybody else feel the same? Or --

00:42:37.008 --> 00:42:49.608

>> CHRISTOPHER KIEWIET: Yeah, any tool we can provide for loved ones such as assistance like this is a positive tool.

00:42:49.608 --> 00:43:02.157

While this legislation does exist in a lot of other states, I think that New Yorkers can make it bigger and can make it better.

00:43:02.157 --> 00:43:05.106

And I think that we have to plug away, you know, Oscar for your representation, and going and speaking with the lobbyists and doing all these things.

00:43:05.106 --> 00:43:06.916

Wonderful, keep up the great work.

00:43:06.916 --> 00:43:13.557

Greatly appreciated.

00:43:13.557 --> 00:43:21.757

It's something I would like to get more involved in because I can just see what that overall benefit is.

00:43:21.757 --> 00:43:25.006

We want to be as parents, whatever we want to be here, forever and always, but I think we also know that's simply not the case.

00:43:25.006 --> 00:43:39.557

That's not how life works.

00:43:39.557 --> 00:43:58.757

And to have an entire network of support for the People around us that we love for their future, and to think above and beyond just ourselves is what's really most important.

00:43:58.757 --> 00:44:14.057

>> NELLE RICHARDSON: I want to also chime into that as well because coming from the point of view of work, where I have seen over so many years, you know, we have -- I have worked through the court system, and part of my job was really to advocate for persons with disabilities.

00:44:14.057 --> 00:44:15.307

I mean, when, when they would just have that person that would come in and say, "Oh, it's not a caregiver," we need legislation to say decision making would really advance this person.

00:44:15.307 --> 00:44:18.156

Give them a voice.

00:44:18.156 --> 00:44:22.137

So we need to really lobby more.

00:44:22.137 --> 00:44:26.956

So we can have it here in New York state.

00:44:26.956 --> 00:44:28.807

As law. To say -- and again, it's not for everybody.

00:44:28.807 --> 00:44:43.058

We also made that clear.

00:44:43.058 --> 00:44:59.157

But for the persons who can benefit from it. We need to have some kind of legislation that says, "Yes, this person may have a disability, but they still have a voice, they can make their own decisions".

00:44:59.157 --> 00:45:03.257

We'll need that power behind decision making, where this person can say, "I know I may not be able-bodied, but I still have a voice," and I need need the them they need.

00:45:03.257 --> 00:45:10.456

We really need to push this more through decision making.

00:45:10.456 --> 00:45:12.407

So we can have this in law here in New York state.

00:45:12.407 --> 00:45:23.957

>> RICK GUIDOTTI: Beautiful.

00:45:23.957 --> 00:46:10.158

>> LIZ GROSSMAN: I'm just going to add here, bunch of stuff going on. Chat is only going to panelists. People are not seeing that. If I may say a couple of things.

00:46:10.158 --> 00:46:12.457

This is from Hezzy, unfortunate, even if -- we talked about this, in New York state, powerful documents change how people support and relate each and solve tough decision making together, effect that process and resulting agreement can have on interpersonal relations between supporters and decision makers should not be under stated, a powerful tool and Chris comment about SDM, advancing in New York lij slart shouldn't be ignored. Odd ru, helpful to hear about, work in conjurngz with guardianshi

00:46:12.457 --> 00:46:22.358

Send this link out, we have links.

00:46:22.358 --> 00:46:36.557

I can copy and paste. Following up with everyone and of course, any and other information will be put on our website as well.

00:46:36.557 --> 00:46:38.258

And then Hezzy, write, just because SDMA [reading] important practice, become better supporters and decision makers, better decision makers.

00:46:38.258 --> 00:46:40.307

This was someone.

00:46:40.307 --> 00:46:54.857

Curious, here's a few questions.

00:46:54.857 --> 00:47:02.408

Curious what would be most, from Amanda, department of education, what would be helpful way educator and related service providers can support families on this journey? That's a good question.

00:47:02.408 --> 00:47:05.808

We could go on and on. 1044 right now. We might have a follow-up.

00:47:05.808 --> 00:47:08.507

>> CHRISTOPHER KIEWIET: To answer really quickly, talk about it, talk about it.

00:47:08.507 --> 00:47:10.958

Talk about it. Advocate for it.

00:47:10.958 --> 00:47:11.857

Talk about it.

00:47:11.857 --> 00:47:22.358

Get it done.

00:47:22.358 --> 00:47:25.758

More people we get on board in if faens of this program here now, legislation will not be able to deny the need at that point.

00:47:25.758 --> 00:47:41.158

If we can get the educators on board.

00:47:41.158 --> 00:47:42.457

If we can get siskratic staff, educators and medical staff in place for him.

00:47:42.457 --> 00:47:47.558

Which is fantastic.

00:47:47.558 --> 00:47:53.457

And we as the parents, we have to say, here's what we're doing.

00:47:53.457 --> 00:47:55.207

Here's why we're doing it, why we need your help in making sure this can be successful.

00:47:55.207 --> 00:47:57.159

We have to talk about it.

00:47:57.159 --> 00:48:07.957

We have to engage.

00:48:07.957 --> 00:48:10.657

And we have to enable our loved ones and the people that need this to be able to have their voice.

00:48:10.657 --> 00:48:25.658

>> RICK GUIDOTTI: Beautiful. Thanks, Chris.

00:48:25.658 --> 00:48:26.957

So, guys, that's probably all the time we have for this webinar. So sorry, we could probably dedicate entire several weekend, so muchination so much information here.

00:48:26.957 --> 00:48:35.907

We'll continue this conversation.

00:48:35.907 --> 00:48:39.207

And create another webinar and continue this conversation based around this film. Our experiences here in New York and round country.

00:48:39.207 --> 00:48:41.257

Looking for ways to keep this dialogue going.

00:48:41.257 --> 00:48:43.307

Introduce this to healthcare providers.

00:48:43.307 --> 00:48:52.806

And healthcare providers in training.

00:48:52.806 --> 00:48:57.907

So thank you, all. Thank WITH foundation for their support. His will send out survey for everybody.

00:48:57.907 --> 00:48:59.007

You can add comments what you like about this film.

00:48:59.007 --> 00:49:02.207

Direction.

00:49:02.207 --> 00:49:08.307

And things we can add to our site.

00:49:08.307 --> 00:49:29.708

We'll add to our website. All the different key links, give you more information you need.

00:49:29.708 --> 00:49:31.658

This is only a 10-minute film, not giving you everything you need to know about Supported Decision Making and how it's evolving every day, but we'll give you opportunities to start this conversation, heard not just in our community, but in the community of healthcare providers and education.

00:49:31.658 --> 00:49:35.157

Liz, you okay?

00:49:35.157 --> 00:49:37.907

>> LIZ GROSSMAN: We'll have recording of this webinar, right?

00:49:37.907 --> 00:49:47.907

Anyone not able to attend today.

00:49:47.907 --> 00:49:54.207

And another great question. How would you like to see these resources seen in medical schools? Programs? Great questions there. This is just a beginning.

00:49:54.207 --> 00:49:58.426

>> RICK GUIDOTTI: Beginning. Thank you, all, amazing!

00:49:58.426 --> 00:50:14.557

>> LIZ GROSSMAN: Thank you, guys! Thank you all so very much!

00:50:14.557 --> 00:50:16.807

>> RICK GUIDOTTI: Thank you. Thanks, Jim, I saw your comment. I'll reach out. Thank you, everybody! Thank you, rick, thank you.

00:50:16.807 --> 00:50:19.807

>> PARTICIPANT: Bye!