

ROUGH EDITED COPY

BURTON BLATT INSTITUTE
FROM THEORY TO PRACTICE:
SUPPORTED DECISION-MAKING IN EDUCATION
MAY 25, 2016

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>> CELESTIA OHRAZDA: Good afternoon and welcome to the national resource center for supported decision-making webinar series. This is a test for the captioning. Captioning is now available. Select the little CC icon up in the audio video panel. This will turn on a separate window for the captioning. Thank you for joining and testing early.

The webinar will begin in about 10 minutes at 1:00 PM Eastern, that is 12:00 PM for all of you on Central time. This is just an audio check.

>> MICHAEL: Celestia?

>> CELESTIA OHRAZDA: Hello there.

>> MICHAEL: Hi. You can hear me but we are still in a holding room, right?

>> CELESTIA OHRAZDA: No, everyone can hear you. Your audio is unmuted. You are not muted, we can hear you.

>> MICHAEL: Okay, so we [indiscernible] early. To move slides on the screen, are you doing that?

>> CELESTIA OHRAZDA: I have gone through with Morgan and Laura -- and both of them will be advancing their own slides.

>> MICHAEL: Okay. So right now I have the main slide up, national resource center for supported decision-making, and part one. [indiscernible]

>> CELESTIA OHRAZDA: Yes, that is exactly what you should be seeing. You are in good hands, Michael.

>> MICHAEL: Okay, all right, thank you, Celestia.

>> CELESTIA OHRAZDA: You are welcome.

Good afternoon and welcome to the national resource center for supported decision-making webinar series, moving supported decision-making from theory to practice.

This is part one of our webinar series, supported decision-making and education.

We have Laura Butler and Morgan Whitlatch with us today. We will begin the webinar in about five minutes at 1:00 PM Eastern time, that is 12:00 PM Central time.

This is our final audio check. As a reminder, all telephone lines and microphones for participants are muted.

If you have any questions either technical in nature or for our presenters, please type them in the chat area.

Closed captioning is available. You can select the CC icon, it is in your audio video panel.

This session will be recorded, so feel free to share it with any of your colleagues that may have missed this session.

Thank you for testing your session ahead of time. This is a final audio check.

[Recording started]

>> CELESTIA OHRAZDA: Michael, whenever you are ready.

>> Thank you. We are going to get started. Welcome, everyone, to the national resource center for supported decision-making webinar series. The next generation of freedom and self-determination, moving supported decision-making from theory to practice.

This is the first in a three-part series. Today's action will be focused on supported decision-making and education.

My name is Michael Morris, I am the Executive Director of the Burton Blatt Institute. And today I will be facilitating this webinar.

Before we get started I want to share some information and answer some of the typically asked questions.

Today's webinar is being conducted using Blackboard Collaborate. This system makes it possible for us to conduct workshops over the Internet from just about any computer with an Internet connection and web browser.

Unfortunately, there may be computer issues inherent in your system that are beyond our control. Which is why it is important for you to check your systems prior to this session.

Our IT staff are available upon request to review with you in advance of the session. Once the webinar begins we are unable to troubleshoot, unfortunately, any technical issues.

This session is being captioned. To turn on captioning, please select the CC icon in the upper toolbar to open a separate window with captioning.

Today's session is also being recorded and archived for future use. A link to the recording and presentation will be posted on the national resource Center for supported decision-making website at SupportedDecisionMaking.org.

Please share this webinar and its archived version freely with interested people you may know who may have missed the opportunity to participate in today's session.

Also all participant's microphones and phone lines are muted. If you have a question, please type it in the chat area.

At this time we are advising you to close all other applications you may have running on your computer because they may interfere with your successful experience today.

I'm pleased to be able to present to you our two experts who will be leading the webinar today.

The first is Morgan Whitlatch, the legal director at Quality Trust for individuals with disabilities in Washington DC.

Our second expert is Laura Smith Butler, research policy administrator of the national core indicators at the human development institute at the university of Kentucky.

Morgan is, as I mentioned, the legal director of Quality Trust. He is also the project director of the national resource center for supported decision-making. She has dedicated her legal career to working with and on behalf of people with disabilities on critical issues involving capacity and the right to self-determination, community integration, living life free from abuse and neglect, and accessing public benefits and services.

Morgan has extensive experience implementing systemic policy, practice, and training initiatives including those of the national resource center on supported decision-making which is funded by the administration and community living at the US Department of Health and Human Services. It is also part of the Jenny Hatch justice project. Both are dedicated to advancing the right to make choices of people who live with disabilities or people who are aging or elderly.

Morgan co-represented the Jenny Hatch Justice Project fighting for Jenny to engage in supported decision-making as an alternative to permanent plenary guardianship.

Prior to joining guardian trust in 2009, Morgan was an attorney at the Rhode Island disability Law Center which is the state's protection and advocacy system, PNA, for people with disabilities in Rhode Island.

Morgan graduated with honors from Georgetown University Law Center and with further honors, Phi Beta Kappa, from Wesleyan University.

Laura Smith Butler is the research policy administrator at the national core indicator human development institute university of Kentucky. Laura has a BA degree in health care administration from Midway College and a Master's degree in rehabilitation counseling in Kentucky. She has worked with people with disabilities for over 20 years.

Currently her work at the university of Kentucky human development institute involves three distinct projects; national

core indicators, supported decision-making, and the quality of life survey project.

Let me turn now to Laura to begin the presentation today. Thank you, Laura.

>> LAURA BUTLER: Thank you.

Welcome, everyone. I want to apologize, my allergies are getting the best to me today so if my throat is scratchy or if I start [indiscernible], that is why.

In Kentucky we are just kind of getting started with supported decision-making so a lot of our stuff is still training people about what supported decision-making is in that it is even a thing.

This is usually the very first slide that I start with when I am doing any presentation. This is one of the definitions of supported decision-making. It says supported decision-making is a recognized alternative to guardianship through which people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face so they may make their own decisions without the need for a guardian.

That is just one of the definitions of supported decision-making, and it is a pretty good one, and that is usually where we start. And I know that Morgan is going to talk a little bit more about why supported decision-making is important in her presentation.

So here in Kentucky, as was mentioned, I am doing the national core indicators project here, so I have this data handy. And in Kentucky 57 percent of the people that we surveyed have a full guardian or are under full guardianship, and 2 percent are under limited guardianship.

And of the people who were identified with a mild intellectual disability, 43 percent of those were under full guardianship and 3 percent are under limited guardianship.

So that means 50 percent of the people in Kentucky who we surveyed were identified with a mild intellectual disability are under guardianship.

And then you can see the other numbers. They predictably go up with the severity of the identified intellectual disability. 61 percent of people with moderate intellectual disability are under full guardianship, 87 percent of people who reported having a severe intellectual disability or under guardianship, and 92 percent of the people identified as having a profound intellectual disability were under guardianship.

And that is just for Kentucky. Our numbers are a little higher than the national average for the national core indicators.

So guardianship is typically sought, at least for people here in Kentucky and I think nationwide, when a person turns 18. In Kentucky the law says that the age of majority for a person with an intellectual developmental disability is 21.

In the school systems they follow FERPA which says it is 18. So they recommend that families turn to guardianship when the person turns 18.

What we have learned and what is supported by national research is that a lot of people are recommended -- a lot of families who seek guardianship, it has been recommended by the school system.

So what I have heard from several families is that the school system starts talking to parents about this when their child is as young as 13, and sometimes younger. So they are kind of prepped for this starting when their child is at a relatively early age.

The reason why this is significant is because school systems are the biggest kind of on-ramp for guardianship. So if we can stop it there and show people that there are other alternatives, that would be a big thing.

So for alternatives to guardianship, we're just getting started with this in Kentucky, so a lot of people don't know about it, and that includes professionals, that includes school administrators, and teachers. They just don't know that that -- that there is anything else. It is either guardianship or nothing.

As you can see by the data on the previous slide, even limited guardianship is probably being underutilized.

So when people find out that there is an alternative and we talk about supported decision-making, they are interested. But it's

a little bit more difficult for them to see how they can implement this because unlike so many other things in the school system and in the disability field in general, there are not these concrete steps and procedures and models that they can use to implement it.

Because supported decision-making is very individualized and is different for everyone, it is more of a paradigm, it is not a model. So that makes it a little bit more difficult.

So what we try to do is to demystify supported decision-making. We try to make it real. So this is my little -- it is not in the realm of unicorns and yetis, it can relate to subjects you already know in demystifying supported decision-making. We compare it to student led IEP, IDEA, both of these are things that school systems should be very familiar with.

Self-determination has been discussed for years, and that is at the heart of supported decision-making.

In Kentucky the vocational rehabilitation office uses PCEP, the arson centered employment plan, which is the same concept as supported decision-making.

And then we talk a little bit how everyone uses a form of supported decision-making in their lives. It could be with helping to make decisions about medical care, your taxes, car repairs, things like that that everyone whether they have a disability or not uses supported decision-making. I don't know anyone who makes every single decision in their lives independently. A lot of people seek out either the advice of experts or friends, family members, things like that. So it is not really that foreign a concept.

Also demystifying supported decision-making shows real world examples. We talk about the DC public schools and we will talk more about that later. I talk about the law in Texas, and that picture there, the estates code, that is from the actual form with the Texas law. We talk about how they are doing that in Texas. There is an example of the supported decision-making form for the DC public school system.

And Leslie I will talk about Jenny Hatch and her case. [indiscernible] Jenny Hatch justice project. She mirrors what a lot of people that I have talked to see in that she was in a situation where her guardians were really overreaching what they should be doing as guardians, and now that Jenny is not under

guardianship and doing her own thing and using supported decision-making to do that.

So that is how supported decision-making is being used in a practical setting to improve the lives of a lot of people.

To further demystify supported decision-making, I gave an example of what a supported decision-making team could look like. So maybe the person has a friend who can help them with transportation. And maybe their mom is an accountant so mom can help with finances. Sister might be in medical school so she will help with medical decisions. And there is a cousin who was at the same age who might help with social or community issues.

And because supported decision-making will look a little bit different for everyone, the team will look different for everyone. So this is just one example of what that might look like for a person.

We also discuss some of the commonly given reasons for guardianship, and these are actually some things that I list that are not good enough, that just because you have X disability does not automatically mean that you should be put under guardianship.

Just because you are X number of years old, whether it is 18 or 82, does not necessarily mean that you should be put under guardianship.

Because you need help. One of the things that I will talk about in my presentation is about how everybody needs help sometimes and everybody makes mistakes, and that is not automatically mean that you need a guardian.

Because it is always been that way. That is an excuse that even if people don't say it out loud, they kind of imply it. This is just the way it has always been done. And that is really never a good enough reason to do something.

And then because it is for your own good. We don't all always do things that are for our own good, and a lot of times guardianship is given as being what is for a person's own good.

So those are some examples of commonly given reasons for a person being put under guardianship that may not be by themselves enough to justify that.

In Kentucky, as we have been talking this year, and a little bit last year about the supported decision-making for people across the state, the main thing that we find out is that people just don't know that there are any alternatives.

They know that there is guardianship, and then there is not guardianship. And not a whole lot in between.

And in Kentucky when a person is put under guardianship, they go through a jury trial. So the person has to go to court and they have sometimes a team of people stand up and say everything that is wrong with them in front of a jury. And then the jury decides whether or not they feel the person needs to have a guardian.

And it works different ways in different counties, but it's typically the same judge, the same team that evaluates, so it is going to be the same social worker, doctor, everybody is going to be the same -- the same team that evaluates everyone who seeks guardianship. So it is kind of a weird system.

But it is something that has concrete steps, that has a history that people know about and that they get.

So that is where when we talk about alternatives people get a little confused. A lot of people are interested in finding out more about supported decision-making, and they will often say okay, where can I go to have someone do this for me? Which is a theory to practice issue and that we are still working on that here in Kentucky, and it is not like guardianship where the process is going to be the same for everyone. It is going to look different for every person.

Education professionals are kind of leery about recommending this or trying to implement it because -- with their students -- because it is not policy, it is not a thing that people know about. It is still kind of, even though we have been talking, it is still this foreign thing that people have trouble wrapping their brains around at this point.

So we're still very much working on just getting people comfortable with the concept.

The other thing that we have learned that was surprising to me -- it was not surprising to some of the other people that I work with -- that a lot of professionals, even the legal professionals who do this, don't really know the ins and outs of

the Kentucky guardianship statutes because they actually support using supported decision-making within the guardianship, but everyone from the supported employment professional, a case manager, and even the wards themselves feel like the guardian is the ultimate ruler of the person.

And so the person is often afraid to do anything without the guardian saying it is okay. The professionals are not comfortable doing anything until they get the guardian's permission. So that has been another hurdle, is even the people who are under guardianship are often under this kind of overbroad form of guardianship that does not support what the Kentucky statute says guardianship should be.

The other thing that I hear almost every time is I had no idea this was an option, or if I have only known this, I would not have gone straight to guardianship. We would have tried this first.

And you know, I had a sister who was having a guardianship for her two sisters who said if I had known about this we would've never gone through guardianship, it would have been easier for everyone if we had just tried to supported decision-making.

And a lot of people are using supported decision-making without knowing it kind of within the guardianship relationship, which is good. But once a person has guardianship status and they are kind of in the court system and at the mercy of the court, if, God forbid, something happens to their guardian was doing it right -- so letting people know the perils of what can happen when you are in that system is another thing we try to do.

But just finding out that people really want to have an alternative but just don't know where to go or are never told that there is anything between full guardianship and nothing -- it's been really interesting to talk to people across the state. People have actually been more receptive than I expected them to be. They really see the value in supported decision-making and just having it as an option for people so that they don't have to be in this legal relationship.

One parent said that they now have to do a bunch of paperwork now just to be a parent to their child because there were all sorts of financial reports that you have to turn in and all of these things. So just knowing that there is an alternative like supported decision-making and moving to more of a practice and

helping people to move into that supported decision-making relationship rather than a guardianship relationship.

So what are we going to do with all of the stuff that we have learned? Well, the first thing is we are going to keep talking about it. We are going to talk to as many groups as we can about what supported decision-making is and how people can use it.

To do that we need to find some more money. So we need to work on looking into more funding streams, new funding streams, work with some more partners to help keep the conversation and the momentum moving, which is always a challenge.

So we want to work with individual families to put this really into practice. Last year at the Kentucky guardianship association there was a mother there who had a son in school who was 13, and the school system said when he turns 18 you need to get a guardianship.

So she went to the guardianship association conference to learn about guardianship. And when she was there she heard about supported decision-making. She was one of the people who said I had no idea there was another alternative.

So she is now trying to see what they can work out so that she does not have to have guardianship over her son. So we want more of that to start happening.

What we really want to do and what is really important is to shut that front door of the school system of guardianship. That is where most people here about guardianship, that is when people are put under guardianship when they are 18-ish. So that is really important, that we get those people before they get into the guardianship.

So we want to talk to as many parents of school-age kids, school systems, self-advocates, everyone so that as many people as possible know about this so that we can kind of stop that [indiscernible] into guardianship.

I am also working on a presentation in collaboration with our Kentucky protection advocacy office to clarify those laws we were talking about in Kentucky so that people understand what guardianship is and we understand what guardianship is not.

And then we also talk about the alternatives. So that has been working well at our [indiscernible] advocacy office is a great ally in this, they really support it and they do everything they can to help promote this.

When someone invites them to talk about guardianship, they will invite us to talk about supported decision-making, so that works out well.

So now we are working on what are we going to do next. So the very first thing is working on talking to the special education directors in the state this summer when they meet just to make sure that I am able to touch as many school systems as possible so that they know about alternatives.

We are going to be mailing basic informational cards with resources to attorneys, judges, medical offices, schools systems, just to kind of get the seed in their head. And we are going to target attorneys who do disability law and also attorneys who work on guardianship things.

Again, people looking for my money so that we can keep doing what we are doing and expand it.

This fall we are hoping to do some sort of forum or workshop with Jonathan Martinez. He is coming to speak to our Kentucky guardianship association conference. And we want to try to get maybe some providers and school systems involved in something where we can talk about the practical applications for supported decision-making and how people can use it in their practice.

We also want to continue to get other state agencies and organizations involved in this, especially those who deal with the transition from school to the adult world. So we want to talk to self-advocacy agencies, we want to talk to and we have already talked to a transition group here in this state. We want to make sure these folks who are involved in helping people transition from school to adult life know about this option of supported decision-making and why it can be a good thing, or the person, as they move into adulthood, a lot of the things that people will use within supported decision-making are great skills for employees. So it might make the person a better employee if they are practicing good self-determination and supported decision-making.

So we need to create some good buy-in within people and agencies are within the state so they can also help promote this.

So that is where we are here. We are still trying to get the ball rolling a little bit. But we have gotten a lot of good feedback and a lot of good buy-in from some people already. So it is going, we just need to work on keeping it going at this point.

So now I will open it up if anyone has any questions.

>> MICHAEL: Yes, Laura, this is Michael Morris. And a couple of questions to ask you.

People of course deal with the rules that are in place under IDEA as it plays out with the state education agency and local education agency. Have you been able either at some formal level either at the state or at a local education agency level to get into a serious discussion on moving away from what is all too often the standard practice across the country were using transition where parents are given that recommendation that you need to move ahead immediately with guardianship, and I wonder if you have been able to kind of make some headway inroads with actually the SCA or the LEA?

>> LAURA BUTLER: Right, so what the state level we have not been able to kind of infiltrate that yet. The great thing about being here at the human development institute at UK is that we have so many other projects, and some of those projects do directly work with the Kentucky Department of Education.

So I'm working with those folks to kind of help me get an inroad into people who are going to be the most receptive to this idea so that we can work on moving that into the regular transition process.

Does that answer your question?

>> MICHAEL: Yeah. I look at it from the other side which is families that -- you begin to talk about the alternatives, and as you said, there was a lot of misinformation that is floating out there.

Thinking about the audience that we have, we have educators, policy members from across the country, we have parents and self-advocates, what suggestion would you give to people working with families or families directly to gather more information that will help them understand better this option of supported decision-making?

>> LAURA BUTLER: Yes, so I think that showing what is at the heart of supported decision-making, the concepts of self-determination and the skills that people need to make decisions and showing how that translates into -- and I think Morgan is going to talk about this a little bit -- but how that really translates into a lot of better life outcomes. Everything from physical to psychological health, people have better higher-paying jobs if they have more self-determination, so just kind of showing the practicality of using supported decision-making and the benefits for the person who was doing it, and the family -- I mean, if the person is able to help make their own decisions and have more self-determination, that is going to kind of make it easier on everyone involved because they are not going to be so reliant on the family members or friends or whoever it might be who was trying to help them in the guardianship.

>> MICHAEL: Excellent, thank you. And a final question, as you look ahead over the next several years, what you think the future of supported decision-making is likely to be in Kentucky, particularly targeting where we are today focused on youth in transition and working with families that are dealing with the K-12 education system?

>> LAURA BUTLER: Well, my hope is that we move forward to something that looks more like what is happening in DC that Morgan is going to talk about, and that self-determination and supported decision-making are being used throughout the entire K-12 system so that people are coming out of schools prepared to make these important life decisions and that supported decision-making, alternatives to guardianship, are just part of the transition conversation automatically and it is not an anomaly if someone wants to talk about something other than guardianship.

So we really want to build on the base that we have started. I think that as more people go to national conferences and hear about supported decision-making, and that is a thing that a lot of people are doing, I am hoping that is going to show everyone yet, this is not just what Laura is talking about, but this is something that people across the country are doing, it is a movement and I'm hoping it will gain more momentum, and that will help kind of pushed us into moving forward with using this throughout the state, throughout the school system, and the route transition.

The challenge, of course, then is to keep it at the heart of what supported decision-making is supposed to be and not just a different form of guardianship.

So there are some challenges with that, but I think that we have a lot of good opportunities and some good directions to go in here.

>> MICHAEL: Excellent, excellent. All right. Laura, thank you for your presentation and your insights and perspectives.

Let me turn now to Morgan who will take us from Kentucky to looking at policy and practice development in the Washington DC schools. So Morgan, let me turn to you.

>> MORGAN WHITLATCH: Thank you so much, Michael. And thank you, Laura, for your great description of supported decision-making and the Kentucky experience.

Now that we know what supported decision-making is, the question becomes why, why use it in school. And as Laura said it really comes down to better life outcomes.

It comes down to self-determination which is an ability to somebody to be an actor in their own life, to act rather than be acted upon.

Research has shown that people have better life outcomes, they are more independent and integrated into their communities and healthier and greater able to resist abuse when they have self-determination.

Research has also shown, on the other hand, that when people are denied self-determination, they can feel helpless and hopeless and self-critical. Many of us are very familiar with the concept of learned helplessness and that can be a real barrier for people with disabilities who are not supported to for themselves.

People who are denied self-determination can have low self-esteem, passivity, feelings of inadequacy and incompetency, it can affect or decrease their ability to function. And that is true of overbroad and over funded guardianship as well.

Last year in April at the national resource Center, we held a webinar for an introduction of supported decision-making for youth in transition, and we pointed out in that webinar that the

evidence is also specifically there for students. Students who have self-determination skills are more likely to successfully make the transition to adulthood. We know that transition can be a very challenging one. They are more likely to have improved education, employment, and independent living outcomes, and that is the reason why we are focusing on supported decision-making particularly within the educational context.

But I think one of the most powerful reasons to promote supported decision-making and self-determination comes from the words of a parent advocate in DC named Herbert King who powerfully tells us why he supports his son Ryan in making his own decisions.

If you have ever met Ryan, you would know that he is a great advocate. He is deeply involved in his community and is an advocate not only for himself but for other people with disabilities in DC and beyond. And his story was featured in the Washington Post last September. He has been working independently for over 12 years, he manages money, volunteers in the community, he has dreams of owning his own business and he is happy to share that with you and what his plans are when you ask him.

And his parents, Herbert and Susie, support them in doing that. Interpret describes why in and review the posted on the supported decision-making.org website. He says Ryan is a whole person. He focuses on the fact that decision-making processes are part of what it is to be a whole person and that to deny somebody that opportunity is to destroy selfness and being whole.

And yet when Ryan turned 18, his parents were told they had to become his guardian to get services. Even though he did not want a guardian and they certainly did not think that he needed one. So they are working out to get Ryan out from under guardianship so that he can be legally recognized to make his own decisions with support, but they are also engaging and supported decision-making so that he continues to build the capacity to make his own decisions.

You can learn more about his powerful story by visiting a website. And unfortunately the advice that the parents got in DC for Ryan was not unique. Despite all of the benefits that -- a better life outcomes was supporting self-determination, guardianship really hasn't still is the default option for students with intellectual disabilities.

Based on a 2015 survey that was conducted school personnel were actually the most frequent source of recommendations that parents seek guardianship, and Quality Trust felt that anecdotally, we get a lot of calls from parents who say the school told them to get guardianship.

And the landscape in DC, I want to give you an idea about what it looks like in DC and where our advocacy strategy had to start by looking at what is this now. In DC almost 70 percent of the people with intellectual and developmental disabilities served by the department on disability services have a guardian or substitute decision-maker they did not appoint.

In the US over all we have found that over one half or fewer of people reviewed were exercising choices about home, work, goals, or services in a way that was meaningful to them.

So that is the challenge we faced when we were looking at the system within DC. And I'm going to put on my Quality Trust have now a document a bit about advocacy efforts that we have been involved in over the last four years to try to change the landscape in DC.

In DC and in contrast to Kentucky to a certain extent, when students turn 18 special education rights that their parents had automatically transfer to the student even though they can remain in special education until they turn 22. This is called the transfer of rights, and that is a phrase that is frequently used with parents, and it is supposed to trigger a meaningful discussion around the IEP team table about next steps.

About four or so years ago Quality Trust begin concerned about a pattern it was seeing. It was seeing that around this time when this discussion was supposed to be happening, the parents were calling us and saying the school told them to get guardianship.

They had not been told that there were alternatives to guardianship and they felt like that was their only option because the message they were getting, whether accurate or not, this is the message that they were getting, that they would be cut out of the child's special education planning if they could not get guardianship when the child turned 18.

And we also learned anecdotally in some cases schools were not informing parents about IEP meetings after a child turned 18 or

allowing them to participate even when the student wanted their help.

So we try to delve deeper to understand why this was happening. And we found out that part of the problem had to do with the DC public schools transfer of rights guidelines.

Under those procedures if parents told school employees listen, I am concerned that my child cannot make decisions and they need some help, in those circumstances employees had to revert the parents to the DC Superior Court and the government for information for obtaining guardianship. The parents were not given any other information on less restrictive options like supported decision-making or [indiscernible], and so we were realizing this was one of the reasons why this was happening and we were getting all of these kind of calls. And that they needed to be some policy change.

So what did we do in the face of this, how will we fix the landscape in DC to include these choices? And we decided that we were going to be collaborating with a variety of partners within the advocacy community, self-advocacy community, and parent groups in DC to ask for change, to ask for change at the state level in our office of the state level of superintendent of education, and we did a call to action letter that had a number of sign-on from disability rights agencies and parents groups and self-advocacy groups across the area to push for change to the policies and procedures and to educate about the civil rights of people with disabilities when it came to decision-making.

This resulted in a number of meetings with the DC office of state superintendent of education and CPS. And we were concurrently, however, also doing public education and training, the same kinds of things Laura is talking about, two families and two educators about how young adults with disabilities can be supported in making the decisions and the transfer of rights and how that very process should be happening even earlier on so that they can build decision-making ability and have the opportunity to be able to be engaged in their lives and in making choices.

This is an extensive effort, and ultimately as a result we were able to get a revision to the DC public schools guidelines. And it resulted in both a change that expressly recognized supported decision-making, and this was actually the first DC level agency to recognize expressly that term, supported decision-making, and

to define it in its policies and procedures. So it really was -
- we were a leader in this area and we developed the supported
decision-making form that we talked about as well in Laura's
presentation.

And really that supported decision-making form is a FERPA
educational release of information form, or a for platform. It
is allowing for the student to identify supporters and then to
allow the school to share information with those supporters so
those supporters can continue to support the student in making
their own decisions.

So really any adult student should be able to find a similar
kind of FERPA form. So it can serve as a model for other
jurisdictions within the nation.

DCPS also began to introduce supported decision-making beginning
in pre-K, and I see this in part because it is still an ongoing
process. They only just started to do this around 2013. So it
has not reached certainly the students who are no longer in pre-
K, but it is still progressing and trying to develop the
curriculum for older students and younger students. So it is a
work in progress with the DCPS, but there is a commitment on
their part to try to build the capacity to make decisions for
the students to bring the system and to recognize the key role
they can play even when they are not adults.

For more information about that particular curricula you can
look at an archived webinar from last April in which
[indiscernible] who was the transition team director and DCPS
presented on those particular efforts. It was a huge
development and the commemorative DCPS to allow the supported
decision-making and reach out to its transition teams to educate
them about this and to be a partner with Quality Trust in this
effort was key to being able to [indiscernible] the work in
progress we are hearing right now.

However, we found out that our job is not done. We realize that
we needed to have more reform and advocacy. We had some
sticking points in particular.

First, DC [indiscernible] is not the only game in town when it
comes to preventing public education with an ever growing
population of students who are in public charter schools.

The revised DCPS transfer of rights guidelines that we worked so
hard to get revised did not apply. And we try to get the of his

of the state superintendent of education to issue regulations I would apply to the charter school and while the schools in the district, but we find that we were hitting a wall in that regard.

Secondly we also found that there were instances where DCPS and schools were not recognizing other less restrictive alternatives to guardianship like educational powers of attorney, and while we of course prefer to support supported decision-making, some of the students want the parents to continue to make educational decisions and they want to do that voluntarily. And why did they want to do that? I think that in and of itself, in the cases I was involved with, was very educational to the need for reform and how we handle IP meetings, and the IEP team meetings can be very contentious and difficult for students.

The way they are currently held now. And do you see is a particularly contagious education world. So you can understand wasted my not want to sit in IEP team meeting that is not too friendly, it is not allowing them to act and to lead the meeting, that is only a talking about the negative or there are battles between the parents and educators about what services they should be entitled to or not.

So for those students that have not had the opportunity since pre-K to be able to participate in their meetings, to be able to lead them, to be able to be a meaningful part of them, you can understand what it would be a very intimidating prospect to have rights transfer to them when they turn 18.

So what do they do for the kind of population? The only option should not be for the parent to go get guardianship. It should be able for the student to exercise the civil rights under state law, and all state laws have power of attorney statutes, to be able to educate an educational power of attorney that is limited, limited to educational decisions and only until they turn 22, that they -- the person can revoke if they change the mind about appointing the parent or they want themselves to be able to make decisions. The, lots of advantages to educational powers of attorney for certain populations.

And we are finding that DCPS schools were not recognizing powers of attorney forms.

And so by this time we realize that there had to be some additional legislative reform in this regard, and luckily enough there was a DC councilmember was running for mayor and who was

very interested in special education reform efforts in the system as part of his platform.

Is staff reached out to us to be educated about these kinds of alternatives they have been hearing about in the community through our training, etc., and we were able to provide guidance about what supported decision-making is, what powers of attorney are, why they are important in the student's life and supporting self-determination.

And the DC special education student rights act was born from that, and especially recognizes supported decision-making. This is something that I highlighted, but it doesn't use the term supported decision-making but having frequently people focus that the term is not on the book so it is not law, but it described supported decision-making. That students can receive support from other adults to aid them in decision-making.

So it paved the way, this concept of supported decision-making, without using that precise term which is not necessary to use although it is like you have to have an alternative to be able to point to the teams talking about guardianship.

In addition recognize that there were alternatives to guardianship like educational powers of attorney, and in doing that it is recognizing that there is a continuum of capacity. They can be people, young people who cannot make decisions themselves even with support, but they are able to decide who they trust to make those decisions for them. And that is the kind of capacity that you need to be able to sign a power of attorney.

So it really opens up a world of alternatives to be considered in DC for students with disabilities.

And now we finally get the office of state superintendent of education to realize that they need to recommend -- intimate regulations not only to apply to DC public schools but to the school system more broadly as a whole. And so in implementing the act they tackled the issue regulations.

And the issue the first of the regulations in July 2015, and they need a lot of work. It is our job to provide input to transit these generalize concept in the legislation into more practical terms that could be understood by both the public as well as the schools that are supposed to be following these regulations.

So with the second notice of proposed rulemaking that was just published on May 13, we now have a specific definition of supported decision-making and they adapted the advocate apostrophe recommendation of what that would look like for adults within special education.

So we're making progress, we are making progress and trying to expand all of that hard one reform that we got in getting the DCPS [indiscernible] revised, and we are getting it to be able to be expended within the system.

But our work is still not done. We have to continue to provide the training for students with disabilities, parents, and educators, and continue that kind of outreach through plain language so people understand how supported decision-making can work like Laura described.

What are some of the mess that exist, had we demystify these concepts so that parents and schools understand that. So the training we are doing is not just for educators, it is for parents and people with disabilities themselves, trying to educate student with disability about whether rights are important, where that you want to try to practice and exercise them, how weekend make it so that the IEP team process is more student friendly so students will be involved in that process.

Individual advocacy. When students are having problems in trying to be able to make the romance of choices because the choices are not being honored, but either the parents or by their school team, we need kids to be involved to show how supported decision-making arrangements can work within the school context.

So we are continuing to try to do our best to do that, to realize that we're not done with this fight, that changes in terms of policy are just the first step, that the needs to be a true translation into practice.

And it has been an honor to be a part of this fight, but it is also been a fight. It has been -- we have had struggles. And I think we are completely willing to share our experiences in DC with other jurisdictions who want to engage in that similar kind of fight.

As I'm sure Laura is as well.

So I'm happy to answer any kinds of questions that you have about the experience in DC. Here is my contact information. Michael, do you have any questions?

>> MICHAEL: I do, I do. Thank you, Morgan, great presentation.

I want to take you back somewhere to about the middle of your presentation, and I thought it was interesting where you offered as, again, an option that is certainly less than guardianship which is the educational power of attorney.

I am sure many of the people listening on this webinar are not attorneys. I think many of us [indiscernible] use the term power of attorney. But I wonder if you could talk about that a little bit more. You talk about it in two ways, both limiting the role of the person who would be selected or identified with the power of attorney, and you also talked about limiting the time.

I wonder if you could talk a little bit more about that as an option which of course would be an option that would exist in any state, although I do know -- and this is just a further complexity here -- each state has a different set of rules kind of like guardianship in terms of what is the form or the template to use that would represent an effective transferring of any responsibilities or any role with a power of attorney form.

>> MORGAN WHITLATCH: You are absolutely right about that, Michael. Every state has power of attorney laws that are different and slightly different. So we have developed a form for DC that is available in the supported decision-making.org website, you have to look to your own state laws to be able to decide exactly what that form would look like.

But all states do have a statutory form that you can usually find online or in the law books.

What a power of attorney is, it is a legal document that a person can knowingly and voluntarily sign that authorizes an agent, which is a different person, to act for them with respect to certain areas in their lives.

So powers of attorney can be really broad, they can cover finances, health care, education, transactions, banking, those kinds of things. Or they can be really, really narrow and

tailored to be one action, one lawsuit, or just to educational decisions.

They can appoint one person to act for you, and they can appoint multiple people to act for you. They can go into effect immediately upon signing, or they can go into effect only if the person who is signing them is incapacitated or unable to make decisions themselves. And that is called [indiscernible] powers of attorney.

So powers of attorney is a useful tool because it can be tailored to the person, the person's wishes and needs. So in this context I'm talking about an educational power of attorney form which could be very focused on educational decisions only, that can last until the person turns 21 or until there educational decisions are no longer being made.

And like any kind of power of attorney, if the person has the ability to make a power of attorney, they have the ability to break it and revoke a power of attorney or cancel the power of attorney.

So it is key to a decision-making authority in a real sense with the student, because the student can say listen, mom and dad or parents or agent, I don't want you to make decisions for me anymore, and they can cancel the power of attorney by letting everybody know that they give it to that it is not in effect anymore.

So that is the reason why educational powers of attorney can be a very useful tool in this context. We have also found that it is a very good way for areas other than education for people to record the fact that they want to have supporters involved in the lives.

So while DCPS does have a form that can be used to document a supported decision-making arrangement, that form does not always exist in other areas like health care, for example, although you can use a release form to get information going within the health care context.

So we have been able to use powers of attorney to say this power of attorney will only go into total effect if I'm incapacitated, and until then I want my supporters to support me and making my own decisions.

So that is how that power of attorney tool can be a very useful one, and I'm happy to talk off-line with people about how they can tailor the DC-based power of attorney to their unique circumstances.

I am licensed to practice in DC and Maryland, but there are other attorneys and other states that we can work with to be able to do that.

>> MICHAEL: And not to belabor this point, but to go even deeper into the weeds, if a student is under the age of majority, which I'm assuming is either 18 or 21, maybe depending upon jurisdiction, is it the student or the student and parents who have to sign the power of attorney form?

>> MORGAN WHITLATCH: That's a very good point. In DC to sign a power of attorney form, you have to be an adult, you have to be 18. But the supported decision-making I'm talking about, possible for powers of attorney, and powers of attorney being signed, they will be signed when the student has transitioned into adulthood and is 18. So that is what the law says, and my understanding is a lot of laws go through powers of attorney that way. You have to be an adult to sign a power of attorney. And it is particularly applicable to transition age youth in special education.

>> MICHAEL: Okay. We did get a comment that in terms of steps and all of the people who need to be educated and learn more about the alternatives to guardianship that we have been discussing is also a focus on clerk of courts. And the comment is they could require that alternatives be explored prior to granting guardianship, maybe to non-lawyers, explain a little bit the role of the clerk of a court, how do they play into the different people involved here.

>> MORGAN WHITLATCH: That really does depend upon the individual state and the role of the clerk of court, so I'm not able to provide a lot of specificity in that respect.

In DC the clerk of court practically has a lot of control in terms of involvement, but it is really the judges that do. So I'm not sure as I can be as helpful as I want to be. But I'm happy to talk with somebody off-line about that if they have questions.

>> MICHAEL: Okay. Thank you. And let me throw out one other question, really a similar question that I posed to Laura in

terms of Kentucky. With what you presented you have had the good fortune with others at Quality Trust to have a champion around the principles of supported decision-making through -- DC has a mayor and you have the city Council, you had individuals who were really willing and able to make a change in the rules.

Any thoughts in terms of -- for people who are working either at a state level, or I wonder even at a local level, at a local level I wonder if a rule change could occur through the local school board. At a state level again it is going to be -- it depends on how a state -- some states have a Board of Regents, they do in New York, or they have some governing body.

But who would you target at a local or state -- and/or state level -- to move to a different process as you and Laura have described today?

>> MORGAN WHITLATCH: I think that school boards can have a real impact in jurisdictions that are in larger states, for example the DC structure is different than other states.

So you can target school boards or those particular agencies within a state that seem to have power, seem to be the one that issue rules that might not be regulations.

And you can frame supported decision-making as really an issue about accommodation. Federal and local law already requires that students have to be accommodated within the school system. Section 504 of the Rehabilitation Act and Title II of the Americans With Disabilities Act.

So supported decision-making is not just a buzzword, it is not something that requires legislative change in order for you to be able to use it. Instead phrasing it as a reasonable accommodation or modification for a person's disability that would allow them to access the support they need in order to make decisions. That is one way of trying to break down the myth that there needs to be a law change in order for people to use supported decision-making.

So you can use that kind of legal hook or that legal argument to be able to try to convince at the local level school boards to make that kind of change without having to have a change at the state level.

So that is one suggestion I have. Laura might have additional suggestions to offer.

>> LAURA BUTLER: Well, I think that -- to speaking for Kentucky -- the overall suggestion would probably have to come from the state level just because locally they are a little afraid of stepping out of line.

But when I have been talking to people, I have been showing them this is a way that you can keep in line with IDEA or if you are looking at transition age in the adult world, supports for community living final rules. These fit in perfectly with that.

So I have been trying to show different professionals how they can use this to either make sure that they are in compliance with new or upcoming regulations on a federal national level, or how they can improve the practices that they use to make sure that they are staying in line with that.

And honestly the hit or miss trial and error method that I have been using is to talk to a bunch of people and see who is most receptive and hope they are at a high level where they can be influential. And you know, it might not be the best method, but it is what I am working with right now.

>> MICHAEL: I would probably add to what Laura and Morgan have said, is ultimately our whole education system, although it is locally governed but has the overlay of rules and laws from the state education agency level or the state Department of Education level so much related to students with disabilities is based on the Individuals With Disabilities Education Act, IDEA.

And it would seem to me all of our advocacy also needs to focus in addition to local and state level at a federal level with the Department of Education, the office of special education program, who could provide guidance as they often do in a letter, or the have other methods of guidance the issue to what they call the state education and local education agencies that could really help accelerate the process of change that has been certainly presented today on this webinar.

So I think it is really all three levels would benefit from each other aligning the vision and values and pulling policy into the 21st century, would make a difference.

There was another question that came from our audience, and that relates to the question of cost. In many states guardianship, handling guardianships is often done maybe -- they say pro se. If a family needed, whether it was as described the educational

power of attorney, or wanted to move to a formula used supported decision-making agreement with the court, do either of you have any thoughts about -- what is one get help with that?

I suspect this is something that protection advocacy agencies, the CMAs, it sells like in Kentucky they are involved, and that might be a source. But are there other ways to answer that question or comment?

>> MORGAN WHITLATCH: This is Morgan. Supported decision-making arraignments and powers of attorney don't always have to involve the courts. So I do think that one thing to note, that they can be less expensive than going to the kinds of court processes for guardianship because that can take time and there can be expense associated with that.

In terms of help and where you can get help, we have heard of people who have been able to get help to the local protection advocacy system, and the national resource center has consulted with attorneys in the PNA system to be able to modify those funds and come up with ways to try to document supported decision-making arrangements and educational powers of attorney, that is one option.

Powers of attorney can also be documents where if it is a simple enough form, we need to think about how powers of attorney is not the kind of document that a person without a disability may be signing that has a bunch of really complicated legalese in it. There are ways to stay within the requirements of the state power of attorney form, and translate things into more plane kinds of languages. So there are aligned powers of attorney form that can be modified as long as they are consistent with law, and I think that there are tools that you can access through PNA system that will be able to point you in the right direction on how to do that.

We're always happy to be a resource at the national resource Center, but to go back to Georgia's question about the question of cost, he said in our area many guardianships are done pro se because many attorneys are too expensive, and that is also true in DC when it comes to parents try to do guardianship as well. And I think we have to look closely at that. Rather than thinking about the barriers -- cost is one of those barriers to guardianship, and rather than focusing on how to make that cost easier for people to bear, we should be focusing instead on less expensive alternatives that can be used within the system that

will allow the person with a disability to continue to make choices within their lives.

>> MICHAEL: Okay. I don't know that I have any further questions. I will just ask Laura or Morgan, do you have any final kind of closing comments to our audience?

>> MORGAN WHITLATCH: This is Morgan, and one of my final comments -- what I did not really talk through as much with some of the lessons that we learned during the process in DC. I think one of the things I learned is something Laura alluded to, that it takes patience and perseverance to make these kinds of changes in this area where substitute decision-making has been so -- substitute as opposed to supported decision-making has been so ensconced in the world where people with disabilities are, it can be hard work, and you have to approach it to a multifaceted approach.

The training initiatives Laura emphasized so well which we are also doing concurrently with the legislative and advocacy initiatives we are doing in the DC context. It requires collaboration building, buy in from not only advocacy groups which is a very important buy-in, but also parents group to have the ear of educators and lawmakers too.

So it is important to be anticipating, like Laura was talking about, what are some of the objections you are going to be getting to using these kinds of resources in using supported decision-making.

So you have to be willing to attack the problem on multiple fronts. And there is some luck involved in the process. Do you have a champion, a person with a disability who you can point to who has a successful supported decision-making arrangement who can put a face to this issue that is so important. People like Ryan King and Jenny Hatch.

And do you have councilmembers or representatives in your state legislature that are willing to champion that issue and have a connection to disabilities. There was some luck associated with the timing of the special education reform in DC, and we recognized that as well. It helped us to create a breakthrough because -- so those were some of the lessons I learned during the process in DC.

>> MICHAEL: Okay. Laura, any last comments?

>> LAURA BUTLER: I was going to say I completely agree with all of that. Here in Kentucky we are still kind of at the scratching and clawing phase, but we have a great partner in our disability office, and I think getting some more allies is going to be really beneficial to us.

And if anyone out there wants to talk about their experiences or learn more about hours, we are happy to talk about that at any time.

If anybody is sitting next to a bucket of money and wants to share some of that so we can extend this, that is great too. But I'm guessing that is not the case.

But I think you all for the opportunity to talk about what we are doing here in Kentucky.

>> MICHAEL: Thank you, thank you both. I do want to remind our audience to take a moment and complete on the screen where it takes you to surveying you about your participation in the webinar today.

As we mentioned several times, please do visit the site of the national resource center for supported decision-making.

And please remember this is the first of a three-part series. More to come. Visit the website for the exact dates in the future.

And I think we all share in this common goal and mission to give all people with disabilities more choices and more control in decision-making that affects all facets and aspects of their lives every day.

So thank you for joining and we look forward to you joining with us in the months to come for the next two parts in the series.

Have a great afternoon, take care, goodbye.