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National Center on Advancing Person-Centered Practices and Systems

Transcript:

“Student Directed Individual Education Plans (IEP): Bringing Person-Centered Practices to Schools and Beyond”

This webinar was originally broadcast on October 27, 2020

>> Bevin: Hi everyone, welcome. We will get started in a moment. Welcome everyone to the first of two NCAPPS webinars in the month of October. We met in September but we have double the fun in October. So today I'm very pleased to introduce the webinar student directed individualized education planning bringing centered practices to schools and beyond. My name is Bevin

. And Alixe -- [inaudible]

>> Hi everyone. My name is Alixe. And I co-direct the center with Bevin and Bevin, I know you are having some technical difficulties so I was filling the time. We will see how your Internet is working now. How is it working?

>> Bevin: I will try one more time. And if I keep breaking up I will let you do the intro. So NCAPPS, the national center of practice systems our charge is to -- [inaudible] promote change to make person centered principles not just an aspiration but a reality and across the people across a life span and we are serious about the across the life span part. So he we we are excited to focus on a public early Life span with IEPs and we go



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all the way to services for older adults. A few logistics before we get started. This is a webinar, you are all muted. But please use chat to communicate. We love to hear from the NCAPPS community in the chat function and you can communicate with one another. If you do want to chat to all attendees, then be sure you select that in the chat box. I believe the default is just a chat to all panelists. If you want to speak with the whole community there are over 300 folks on already. Then you want to select all attendees and panelists.

And you can use the chat for Q and A if you have questions. We will get to those later. This webinar is being recorded. You can access a PDF version of the slides. There is a link in chat that Connor has posted and in a couple of weeks on NCAPPS.acl.gov we will post the full recording, slides. Plain language summary.

Various other goodies for you so you will have this in the future. The slides link again, it is in chat. It's [www.hsri.org/files/uploads/publications/NCAPPS space webinar space slides space](http://www.hsri.org/files/uploads/publications/NCAPPS_space_webinar_space_slides_space) >> Captioner: Sorry. Lost the end of that link. It's in the chats, I will.

>> Bevin: So I would like to have a quick poll. For folks please do select who -- what role you self identify as. You



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are welcome to select more than one role. And if you don't see the poll you can also put your role into chat. We will leave things open for a little while and while people are completing this poll I will remind folks that the link that I read out is in chat both Alixe and Connor have posted. So people should be able to go into the chat function

And SCLIK on the link -- click on the link for the PDF for the slides. If you would like to access those. We will give folks five more seconds, Connor, and we can close the poll.

>> Bevin: Let's see who is here. We have a wide array of people on the call. About a third of you are educators which makes sense given the topic for this webinar. And close to a third of you are social workers, councillors, care managers, quite a few government employees.

And then we have a good group of other folks including folks with disabilities. Family members with people with disabilities. Self advocates. Advocates, etc. Welcome, we are glad you are here. Now I would like to turn things over to NCAPPS project coordinator, Miso Kwak, who is going to say a few words introduce our speakers.

>> Miso: Hello everyone. I'm Miso Kwak. One of the project coordinators for NCAPPS.

Typically I'm in the background during the webinars but today I



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have the pleasure of moderating this panel. As Bevin mentioned I will be talking about student directed IEP and what it might mean to bring person centered practices into schools and beyond.

When NCAPPS chooses webinar topics there are many ways in which we choose a topic. One of them is suggestions from our person centered and advisory leadership group, known as the PAL group. This is one of the topics suggested by the pal group. We are really pleased to be bringing this webinar to you all.

Also, personally, this is a topic that is near and dear to my heart because as I reflect on my own experience as a blind Korean American immigrant, a student who had to navigate the educational systems, I can say that my schooling experience both in Korea and the United States played a significant role in shaping where I am and how I interact with the world today.

And at the core of that experience, especially in the United States, as a student with a disability is the Individualized Education Plan plan or IEP. Whether you are a student, a parent, teacher, or a school administrator or any other role you identify with, personally and professionally, Ingham of us recognize -- I think many of us recognize the importance of an IEP. But feel a great deal of pressure for the



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IEP. As a student new to the United States and didn't know much at all about what to expect, I felt lost and frustrated and a number of IEPs I had to participate in. As I got older I came to know what to expect and learned

How to speak up for myself, but it was a challenging process that took a time to get used to.

>> Miso: I'm excited we get to hear from a dynamic panel and they will share their strategies how to support students to be at the center and in charge of their own IEP processes. So I will now introduce the panel.

First we have Sara who is in her final year at the coting school. Sara is a student with cerebral palsy and she loves art and hopes to study graphic design. We are joined by Mary Abby who is an assistive technology instructor. She is also a graduate student at the University of Massachusetts Boston. She is studying to become a teacher for the visually impaired.

Her passion lies in pursuing equality, equity and diversity within the classroom. Next, we have Lynn. Who will share her experience as a parent of Maggie. Who has cortical visual impairment. She is getting ready for transition soon. An approach to the transition IEPs Lynn has supported Maggie and worked with her team to move towards a Maggie-driven IEP and transition to adult life.



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Next we are joined by Beth who is the proud parent and humble servant of king James. A 20-year-old medically complexed young man. Beth wears many hats. Few of which are a special education advocate, a board member of the federation for children with special needs, and adjunct faculty of the umass program. And Emily is passionate about helping youth discover their areas of unique talent and work with teachers and students To connect those talents to work opportunities and future for the students. That they want to have.

So without further ado let's jump into meeting the panel. So panelists -- I will go ahead and ask you to introduce yourselves. Specifically, please tell us what brings you here and what fuels your heart when you think about student directed IEP.

So Sara, please go ahead.

>> Sara: My name is Sara. Nice to meet you. I'm taking part in this webinar because disabled students need to be able to speak up for themselves. Many students do not have the opportunities to be heard because adults do not feel they can communicate or understand. Students should express their vision.

>> Miso: Thank you. Mary Abby. Could you TROINT dues yourself?

>> Mary Abby: Hi everyone. It's nice to meet you. As a perspective teacher of visual impairments, a students with



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visual impairments. I am interested in helping students find their voice and advocate for their needs. I'm also myself an immigrant from the Philippines. And at this time was -- it is a personal topic for myself as well as Miso said. Because I was able to observe how my parents navigated the IEP system and the school system. So I feel it is important for me to help students navigate that system

Future as well.

>> Miso: Thank you. Lynn, I would like to hear from you next.

>> Lynn: Hi. Thank you, Miso and everyone for the opportunity to join this panel. My name is Lynn Waskelis. I am the mother to Maggie and her older brother. I do parenting with their dad. My husband. My work is not in the world of disabilities, my background is in local history, non-profit and architecture. But today I'm here as Maggie's mom, Champion and advocate. Maggie is a young adult. A joyful friend. Who loves her pets. Her dogs and cats. Her family. She loves singing and music. Food and cooking. Working, making plans and staying busy in courses. In the area of disability she has CVI which is cortical vision impairment and intellectual disability. Notary and sensory -- motory and sensory challenges. She attends a private school that educates



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young people with visual impairment and is a day student there and in a hybrid learning situation where she goes to school two days a week and learns from home three days a week. And I'm hoping by being here today that I can share what I've learned

As her mom and growing into the role of advocate and Champion. And how -- where we are at on her path to self determination. And hopefully assure you that it's always a process.

>> Miso: Thank you. Beth, please go ahead and introduce yourself.

>> Elizabeth: Hi everybody. The way I got into this business and industry was direct result of parenting King James. And one. Reasons why I'm so passionate about this is James is a young man who is so complex. He is nonverbal. G2 fed. Hearing impaired. And wasn't actually able to communicate until he was 18 years old.

And so as a parent it was really important to me to make sure that he had the ability to communicate his wants, his needs, his aspirations. His snarky sense of humor. And all of the things we enjoy about him. And to know that he really was going to have a voice in general. I needed him to be able to communicate. I needed him to be able to read. I needed to know he was going to have choices going forward.



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And so especially in the context of being a young man of color, I wanted him to be able to have the ability to engage in the democratic process, to do voting. To know how to navigate all of those different things. So all of those things were really important to me as a parent. And I bring that passion also into how I support other families who have transition-age children. And helping them to understand how to get started really early on in choosing appropriate life experiences, and employment opportunities when it's appropriate.

So students can literally choose the life that they want to pursue. Rather than it being shaped by a number of adults sitting around a table who think they figured this kid out.

That's one of the reasons why I'm here. I really want to help teams really facilitate hearing from the student and not figuring it out on their own.

>> Miso: Thank you. Emily, would you like to introduce yourself?

>> Emily: Thank you, Miso. This is really a personal passion of mine. All human beings are valued and listened to. I think the IEP meeting is a perfect symbol. That if everyone can get that it is that person's life and that the person who should be in charge of that meeting is that person who it's about.



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And in it my work as a transition consultant I get so excited when I get the chance to work with teams to make that shift so that the student is at the forefront and so that they are listened to, heard, and everything is directed around what works for them and what their goals are and what's important to them.

I was super excited for this discussion and panel. Because I think it is such an important topic to create around and people to really look at how you can do this in your own schools or in your own life.

Thank you for being here and having me.

>> Miso: Yeah, Thank you, all for joining us. I've -- it's been super exciting for me.

Kept me engaged and excited as we prepare for this panel. I can't wait to learn more from you all. So I would like to ask Mary Abby and Sara, what does it MEEP to be in charge of your IEP -- mean to be in charge of your IEP meetings? I would love to hear what you think about that and any examples you would like to share. Mary Abby, please go ahead.

>> Mary Abby: I'm sorry, I was muted. So one thing that means -- that is really meaningful to me is that when I lead an IEP, if I was to lead app IEP I have a voice in all of the different struggles that I have and the IEP team is also aware of my strengths. So one example of



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this would be when I was in high school and I was having a lot of trouble with math class, I brought this up to my TVI, a teacher of the visually impaired and explained I was having a lot of problems understanding the graphics and different layouts Of equations. And I brought it up to my team during the IEP meeting which was a beginning starting point for me to advocate for my different struggles.

I was able to feel I was heard because we came up with a solution the TVI could sit in the class with me and help me understand the graphics and different math situations.

So this is just an example of how leading an IEP can start by speaking up first and then gradually kind of being able to lean more as you move through the process and get older.

>> Miso: Thank you for sharing. How about you, Sara?

>> Sara: One time in my IEP they were not able to address my concerns about my ridiculous friends because when I said I could talk about my friends at my school, they thought I wanted to be a writer and ignoring the fact I was being sarcastic.

>> Miso: Sara, did you have more to say? I wanted to make sure that your remarks were done.

>> Sara: I'm done.

>> Miso: Okay. Great. Yeah, we can -- the next topics which is tools and strategies. Yeah, so I would like to share what is



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your favorite tool or strategies when you are supporting students to be in greater charge of their own IEP meetings and how you are supporting students using those tools and strategies.

Beth, I would like to start with you this time.

>> Elizabeth: I find often when working with students and their families it's very hard for them to figure out how to articulate what they want to do. You know, and especially when you think of the context in even with typical kids at 14 years of age. They don't know what they want to be when they grow up and it year to year which could be frustrated to the parent.

What I find is particularly helpful is to give them a way think about it. What is the end goal? What is what would be considered the good life? So my favorite tool is to use -- if anyone is not familiar with it their website is the lifecoursetools.com. And they have a plethora of tools out there. And the basis for life course is that everybody has the right to live, to love, to work, to play and to pursue their own life aspirations. And I think what we have to do is really work at how do you actually frame that? How do you think that through? That's not a simple question. It gets complicated how you actually access that dream? So WUP of the places

One of the places I start with,



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and I will share my screen. Is what is called charting the life course portfolio.

>> Elizabeth: As we look at this, this is meant to be printed two sided on 11x17 piece of paper. So when I go through this it will seem a little illogical because it looks like I'm flipping all over the place. But if you can picture it being printed that way and opening it up, it makes more sense.

On the right-hand side it talks about what do you like about the person? What do people admire about that person. And what do you believe is more important for that family member? For your person with a disability? And what are some of the best strategies to support that person?

And this is something -- this particular one is written from the family perspective. And very often we are starting the conversation with parents ages 14, 15 and 16. And they are responsible for the IEP and actively involved. We do what we can to help them shake that. We then take them to what's called a trajectory. And within life tools there are many different versions to accommodate a lot of different types of problem solves activities. And in this case we are asking the question, what is the family members good life? What does that look like? And we do that by asking a number of questions. Because



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sometimes when you are at the beginning of the process it's like I don't know what is going to happen. I am just trying to get to tomorrow or next year. The idea of my child being 22 and an adult and possibly doing things I can't even get to right now. Sometimes it's easier to ask the question. What do you not want for your child? Many people know what they don't want. They don't want them isolated. Engaging in certain types of activities.

And a lot of the things we do want are similar to what you think of anybody else. We want them to be loved. We want them to have gainful employment. We want them to feel fulfilled. We want them to feel safe. We want them to have great relationships.

And we look at exPEERNLSs and try to figure out what is going to get us toward that -- experiences and try to figure out how to get to that position. And once we've done that we go to the what's called the integrated star which is on the left-hand side of this now. And the integrated star. One of the things I love about it is families have been so socialized to think only in terms of the things they are eligible for and not in terms of all of the other resources available.

To not only your disabled loved one, but to anybody who happened to live here in the United States. So we look at



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relationships. How can we use those relationships and reciprocal relationships? Who are the people that will care about and for your loved one? Who are their personal strengths and assets? We forget the person is an asset. They can bring things to the table to make it successful. How do we use that? My son was using eye gaze technology to communicate and it gave him access to a whole different world once he was able to do that. All of the different apps and ways he could order his prescriptions online with a cvs app.

We have access to those types of things. And community based organizations and community based resources because we don't think of all the natural resources that everybody has a right to access to, we often don't think of them. The local YMCA. Or national parks. All of the different movie theaters. Whatever is out there for everybody else, our loved ones have access to. And what I find fascinating is that very often it takes a while for parents to get started and their loved one to get started, but once they start filling this in over time you begin to realize that there are a lot of other resources out there

As opposed to relying on your agency supports. And that's when it really becomes exciting. Because people are No longer dependent because we



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can do this if we have this. Or this is the only thing we will pursue because we are only eligible for these things. It opens up a whole other level of creativity that people didn't have before.

And it positions that person to identify what they are interested in and explore all of the possibilities around that.

If you go to that website you will find there are lots of great tools there that will help you with problem solves. And each of these pieces in this large piece of paper they're is two sided, it is one separate document.

So you can tackle that whenever you are in your journey. I recommend this as a wonderful person centered planning tool that you can flex and use at various stages in your journey.

>> Miso: Thank you, Beth.

Emily, how about you? What is -- what tools and strategies would you like to share with our audience today?

>> Emily: Thank you. So one of my favorite tools is is something I like to call prepaving. And it's basically way, way before you ever get to a meeting. If it's an IEP or whatever meeting it is that that person is preparing themselves. And so when you think about preparation to me, IEP meeting is such an opportunity to practice leadership and ownership of your life.

And of course it's going to look



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very different for every student and how they are able to communicate. And how they are able to participate. But if the key is really -- leadership is more an ownership is a feeling, right?

Is a way of being. So as team members, as teachers, as therapists, having chances to practice. Have that student be in leadership roles. Have them get used to their voice being heard and listened to. Talk with them about what do these things mean? Because so many times kids have just no idea what is even being talked in their meeting.

With all of these terms. I'm also an occupational therapist and we have lots of terms. You want the language even being used in a meeting to make sense. And for that person to be so well prepared that when they get to that meeting they are at home. They know what they want to communicate. The team is listening to them. Sometimes it might be in video form.

That they prepared a video and showing that. So that everybody gets connected again to the student's goals and what's important to them and that that is actually what the meeting is about. Nothing other than what is important for the student.

What they want to achieve in the next year. And they are ready and know this is their meeting.

I think it is so important that kid know it' their meeting.



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Because sometimes I heard kids say they didn't even realize. It seems like it's somebody else's meeting. So I think prepping where you are preparing the whole year long with the person, you know. For their meeting. But for their life because it's about their life and having a fulfilling life.

So that is one of my favorite tools I like to call prepping. Preparing the way with the student. So Thank you, Miso.
>> Miso: Thank you, Emily. I remember as we were preparing our webinar this struck me and I resonate with what you just shared. So Thank you so much for sharing this. Lynn, what has been some of your favorite strategies and tools you would like to share?

>> Lynn: Yeah, Thank you, Miso. The things that -- the people that came before me really resonate with me. That we were that family, I was that parent that current even imagine. Don't even talk to me about transition. But it -- it kind of gradually became a reality. I remember when at age 14 the transition planning form came into the IEP and I -- I was like somebody else do this. I can't even think about it. I don't even want to face those life after school. So any way, for me as a parent a lot is kind of overcoming fears. I think like Beth said coming up with a vision feels so important



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to help. You kind of hold steady and prioritize. Because there is so much prioritizing involved. And charting the life tool seems so helpful. I dabbled in them but they are not integrated in the team we have currently. I would say as a parent although I sense their power and I have begun to use them, it feels like I haven't figured out how to bring them on board to Maggie's team.

But however you get to a vision and I think charting the life course tools is a great way to do it. It seems super important. This past year, Maggie, who's communication ability -- she has been quiet at her IEP meetings although she's been attending them for years. In a prepaving way that Emily described, composed for the first time her own vision statement. And she did it in a quiet one on one context with somebody who knew her well. Her speech therapists. And it was over multiple sessions. And she used her Touch chat software on her iPad to discuss her vision. She was -- she did it with the use of prompts that people at her school had come up with. And so for the first time her vision which was read by her speech therapists was front and center at her IEP meeting.

The other tool I found useful is person centered planning meeting. So that is a separate



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meeting from the IEP meeting and I think it is a place for a vision to take shape.

The structure of the meeting is creative and celebratory for the students. It could be a place to awaken that you have a future, that you have a voice in.

It is a place for identifying strengths and barriers. It is a place for nonschool and nonagency people come into play and talk about this person.

It can kind of cohere various planning for that person. And identify gaps, like people gaps, or experience gaps so everybody can accept their course to filling in the gaps as you go forward.

One of the most interesting one I experienced was not at my daughter's person centered planning meeting but one of her friend. And my husband attended it. His passion for music was identified and it was seen that there was an opportunity missing in the school experience.

The school came together and formed a class that has all of these aspects to a performance and communication and practicing. And so it's been -- the class is new this year and it's been a life line to so many students during the Pandemic.

Thank you.

>> Miso: Yeah, as I reflect on the responses that has been shared so far, I think one common thing that is coming up is working together and being



creative. And so I would like to turn to our panelists that are bringing their student perspective and ask what is one way that your parents and teachers can support you to take greater charge or feel more confident in your IEP meetings?

>> Sara: RA, how about we start with you this time? -- Sara, how about we start with you this time?

>> Sara:

>> We are taking a pause and Sara, you may be muted.

>> Sara:

>> Miso: Sara, could you say once again a -- if you said it already and we couldn't hear you?

>> Sara: When I was younger everything was handled for me through my parents. But now I am involved in my meetings and I advocate for what I need. I'm guaranteed to be in the process because it is a goal written into advocate for myself and what I need. -- guaranteed to be in the process because it is a goal written into advocate for myself and what I need.

>> Miso: Thank you, Sara. How about you Mary Abby? What is one thing your parents and teacher can do I guess now it's more of a past tense but maybe you could share an example when your parents and teachers that you worked with them and felt like it was a good collaboration that you were able to take a proactive role in?

>> Mary Abby: Sure, one of the



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things -- I do agree with Sara.

It is important that your team recognizes that you also need to advocate in your IEP meetings. So one thing that did happen in my school team was that I -- it was written in my goals as well I need to learn to advocate for myself. So that helped. The TVI that I worked with and a few other professionals were aware of that. So they did ask me to speak up more. But another thing that I can

Recommend

Is that the student is prepared for the IEP before hand. So a team member could explain the process

To the student and it could entail something like explaining what each team member is responsible for. Because if the student doesn't know what supports are available they don't know what to ask for. It's important that the student is given space and time to speak up in the IEPs and the adults aren't speaking over them and for them. And their opinion is asked for.

>> Mary Abby: I agree with what was said earlier that the student is given a chance to write their goals and state maybe a vision statement which was a great point. That was kind of what -- I did that one year and it helped me understand what I needed to work on for the year.

And the last thing I can suggest is the student is given a chance



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to observe an IEP before they are thrown into speaking to adults about what they want and need so they have an idea what is going to happen when they get a chance to speak up.

>> Miso: Yeah, I think those are some excellent ideas. And I especially resonate with the point writing specifically making a goal to help students encourage their students to advocate for themselves. And I didn't know many people that were sitting my own IEP. I never met you before.

But I guess we are in a meeting together. I guess it is a great point that students need to be given an opportunity to learn more about IEP and going back to the point of prepaving and giving students a time to think more and process more previous, prior to the meetings, those are important points that we can all be taking away.

>> So I would like to then ask -- turn to the panel and ask what words of advice you might have for our audience who joined us today? So Emily, as a practitioner, what advice do you have for other practitioners who want to be more supportive for the students that they are working with so that students are taking greater responsibility and feeling more prepared to lead their own IEP meetings?

>> Emily: Thank you, Miso. It's interesting. I will share a little bit of my own journey as



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a practitioner as an occupational therapist and transition consultant. So it's easy because we get all of this training and it's easy to feel like oh, I have this expertise. I have these great ideas for this person.

And great ideas for goals. Right? But I think the trick that I kind of finally started to see and recognize was I could have the greatest idea in the world, the greatest goal idea, but if it doesn't connect to the student, if it's not something that they want, that they want to work on.

That they are interested. It will further their vision or further their goals, then it's not the right goal for them. So I guess my advice that I give to myself continually

And to everyone is just to continue to tune into the student. Like tune in. Like my goal is how much more can I get to know this person? And sometimes it helps speaking to their parents or other people that know them very well can help bring out something I didn't know. Because maybe they are not able to speak. And I didn't know they loved music.

But finding, what are the passions? What are the things that person loves? And tuning in to who they are as an amazing human being and what is going to help them further? What it is they want in their life? Even if they don't know what they



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want there are things you can see they enjoy.

That they like doing. And assisting them in doing more of those things as they move in their path toward life toward adulthood. I think that would be my greatest advice that I'm continuing to learn myself and practice.

But really tuning into the student and remembering that is what is important is the listening versus my big great ideas we think we have as practitioners that maybe aren't the right fit for -- it might be a good idea but not the right match for that person. So Thank you, Miso.

>> Miso: Thank you, Emily. Lynn, how about you? What advice would you like to give to other parents who want their children to be more proactive and confident in leading their own IEP meetings?

>> Lynn: Thanks, Miso. So let's see, advice for parents. Well, I will start with advice I would give to myself which would be to kind of identify my own -- I've had to identify my own fears and feelings about my daughter first and foremost. About her safety. And then kind of -- you know, this is true of everybody, but especially with people of disabilities. Facing all of our mortality. The fact that if -- that she -- my daughter is likely to outlive me. And so finding ways to kind of recognize those fears. And get



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the support that I needed to kind of face them. And for me it's meant both reaching out to other parents for support.

Finding people who I can buddy up with to doing some of the work it takes to be Maggie's Champion and advocate. That might mean for -- like recently before the Pandemic it meant starting to visit places where she might go to spend her days after school and dog it with another parent.

-- and doing it with another parent. And educating myself. I did a class on transition.

There is any number of ways you can try to learn and that was empowering and helped me kind of come up with a framework.

Because I think transition is where you start to think about the person centered. I would also say what I think like Beth and Emily said is starting early is so important. And I wish we had started earlier. And kind of as a parent breaking down what empowered decision making is. And giving

My daughter, giving kid lots of practice doing that.

And meaningful decisions.

Consequential decisions. Not just decisions about the color of your clothes. But if that's where you are, that's where you are. So that seems -- that's daily. All day every day.

And then I think of person centered processes as a continuum. Person driven. We might not be there. I think of



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myself as next of my daughter.
Behind my daughter. In front of
my daughter. I try to kind of
stay fine tuned about what my
job is and obviously when I can
step back I try to.

Remembering as Emily said to
listen. To step back and
listen. I think as a parent you
know you are kind of pushed into
a role of leadership. And it's
probably the right role. You
are the common thread. You
sometimes are the literal voice
of your kid.

But you might not always know
best. I got to try to take my
cues from my daughter. Take --
listen to team members that work
with her and other settings and
particularly for my daughter
it's about work. She takes
pride in work and shows parts of
herself that we don't see always
at home.

And then I just -- giving her
life opportunities to kind of
understand what self
determination might look like.
It's kind of a lofty concept. I
think we are all -- it's a life
process for everybody, but I
think when you are somebody with
vision impairment and multiple
disabilities the world can
forget that you have the power
to make decisions about your
life, too.

So I think those -- I think that
kind of hits all the marks as a
parent what I could offer as
advice. Thank you.

>> Miso: Thank you, Lynn for
that thoughtful answer. Beth,



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what advice would you like to share with the audience?

>> Elizabeth: How much time do I have? My goodness. When I think about -- we often think about transition and in the state of Massachusetts we think about it at age 14 and in other states it's age 16. And this drives me nuts. Because no place else do we start that late planning for some kids life.

How many times do typical kids get asked the question at 2 and 3 years of age, what do you want to be when you grow up? Right? I encourage parents to start this process so much earlier as Lynn was saying. And so many things that I've heard I resonate with. How do -- there are so much data out there that tells us certain activities that kids engage in throughout their lifetime that prepare for employment. That prepare them for independent living.

A simple thing lying chores. Prepares a child for getting ready for taking responsibility and doing things like that. So I really encourage parents to think about those things early on. You know, the self advocacy piece doesn't have to wait until you are 14 to be included in an IEP. It could be added at 6 years of age. And really just setting up children to really start learning that they have choice, they have a voice.

Allowing the consequences of bad choices to happen so they learn from those. As much as we want



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to give them the dignity to
succeed, they need the dignity
to fail. And feel what that
feels like and take
responsibility for it. And of
course doing it SAFRL.
You know, as you do -- safely.
As you do with any other child.
You are not going to let someone
take their bike down the highway
but give them a context when it
is appropriate to do so. So
when you think of it in terms of
what choices do you want this
child to be able to exercise
down the road? It's every
choice. Going back to my
favorite tools of charting the
life course. They have
phenomenal resources around
helping you understand what are
some of the activities
That typically happen at age 6?
What are some activities at age
9? If you go into that website
you will find what is called the
life stages experiences and
questions booklet. A fantastic
resource for understanding what
that is. Because sometimes we
don't know where to begin.
And then as a parent, don't be
concerned about the fact you
might be a little behind or
haven't done those things.
Start where you are today.
There is an amazing employment
guide that helps understand how
to prepare someone for
employment? There is a lot of
resources very data driven. But
those are the types of things in
addition to creating those
academic opportunities and



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making sure that they can do all of the reading, writing and arithmetic. Let's be deliberate and intentional

About adding the other types of skills. The quote unquote soft skills.

Decision making skills.

Advocacy skills. Problem solving. Perspective taking.

And if you make a mistake, understand that it's okay that you made a mistake. That what is important is you take responsibility for it. Learn

from it and try not to make the same mistake again and apply it to other scenarios. And that can get really complex depending on the type of learner you are talking about.

I know with my son he got to the point where he wanted to engage in some activities because he suddenly had a voice. So he could tell me what he was excited about and what he wanted to do. So we had a conversation. Lynn, one of the things about facing your own fears. My son had the audacity to say he wanted to go to camp and go zip lining.

As you can imagine, I was like I don't think so. Obviously, you are not in a position to make sound decisions. We have to work on that. But I had to stop myself. It was adaptive and the logical thing was all there.

The reasons why it could work.

All the safety measures were there but my mother's heart was going, I can't do that. But I



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had to let him do it. And I loved it. Because he has a need for speed. But we have to allow them to make those choices and then help them to -- and even understanding safety. You know, what is a safe choice? What is not a safe choice? What are the reasons why something is safe? What is the reason why something is not safe? And not look at in terms of limitations, but look at terms in we have to figure out how to do this in a way that is safe given my current being as a person and allowing people to have those choices. I could go on and on but I think the bottom line is position our students to be able make choices. And give them the right to do what we do because every one of us makes stupid Choices all the time. It's okay. But the kids with disabilities and they make a bad choice

And they get labelled for life and never able to do it again. They have a right to make stupid choices. Let them do it.

>> Miso: Thank you, Beth. A common thing I'm hearing from this thread of responses is the importance of listening that I think is more important than ever in every way we are living and experiencing our lives now. And especially when working with young students. I think it is really important to listen. And also this concept of taking a risk that we talk a lot at NCAPPS. I think it's important.



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I can say for myself, there are many things that I'm grateful. The way I was brought up. having the opportunity to do things like roller skating. And activities that people think is too dangerous for a blind kid. So Thank you so much for bringing those points out. I think it's really worth saying it over and over and sharing it again and again. And emphasizing the importance of listening to what young people want and allowing -- and respecting that they are going to take risks. So Thank you.

>> Miso: So now I would like to turn to Mary Abby and Sara. Ask a similar but slightly different questions about giving advice. You know, as we reflect on our younger experiences I think there are many things that we can wish that things had been different. So one question is, one way to think about it is, what would you tell your younger self about leading your IEP meetings and being in charge of your education Alex -- educational experiences? And there are young peeping today that are in the place we had been in our own lives. What advice would you give to your younger self? And what advice would you give to students who are going through the stages of participating And leading their IEP meetings? So Sara, why don't we start with you?

>> Sara: I would say to my



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younger self, don't worry about speaking up for yourself and don't panic. I would tell other young students be confident and brave in yourself for telling your team what you need.

>> Miso: I love the don't panic part, Sara. I think it's really important that being confident and being part of that is managing our anxiety and working with others as we have discussed. Mary Abby, how about you? What would you like to impart to your younger self and other young people today?

>> Mary Abby: So I think they tie together in the sense I would tell myself and other students, that it's important to work with your teachers and team members to learn how to speak up for what you need.

It could be really hard to tell adults what you want or need. And I had a really hard time as a student because I was like they are adults. They know better than me. So how am I going to tell them how to do their job? You know yourself better than anyone else. Tell adults what you need. And you have to know how to do that. One way is to work on different phrases you can use. Work with one individual that knows you better and knows you really well. And have them help you practice different ways to ask for things. And practice speaking up in your daily life. Even with small things. And this is really beneficial



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and it will really help you learn to advocate. Especially if college is one of your goals you have to advocate for yourself. There is not really the same kind of support system. There is a support system but not quite the same. So learning how to ask for things and learning how to identify what you need is really important. And starting as early as you can. I also would say have the team members explain what they do and how they can help you so you have an idea what supports you have. Because in order to ask for supports it is important to know what supports are possible. Another thing I would say is ask your TVI or other team members To expect -- to explain what the IEP process will be. Because you don't want to be surprised. And you want to be comfortable. With what is going to be happening in that meeting. It could be very uncomfortable to have adults speaking about you. You want to understand why they are speaking about you. What they are talking about. And you want to be included in that process. So definitely ask to be informed before the meeting. And ask your professionals to help you find your voice in any way that you need them to. If that's making everything in written format or you know, just Providing you some resources and supports to help you find your



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voice. And if you don't know how to speak up, you are not going to know what to say to these group of adults sitting around you when you time comes. So you want to have those kind of tools ready when ever you need them.

>> Miso: Thank you, Mary Abby.

Yeah, so this concludes the prepared portion of our panel. I took a peek at the chat and it seems like there has been a lot of activities going on as usual. I'm really glad to see that. So I will turn it over to Alixe who has been monitoring the chat more than I have this time around. And she will ask some questions to the panelists. I think there have been lots of links floating around the chat. And after the webinar we will be gathering all of those things and sharing it on our website in a few weeks time. So yeah, I would like to thank the panel for working with me and it's been really fun. And meaningful personally. Now let's hear from you, the audience, what questions that you might have for our panelists.

>> Alixe: Thank you, Miso. And Thank you to all of the panelists. Again, you are right Miso, it has been as expected a lively chat session. And I just love the people are so incredibly generous with their resources. We did have a few questions come through and our panelists have answered in a couple already. But there are



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some I would like to bring forward to the panelists.

I'm going to start with one.

There has been quite a lot of conversation about getting people involved early in student directed IEPs and in a number of different ways that people could get people involved early in the IEPs. So this is a question that I am going to put to Sara and also to Mary Abby. And parents involved.

And the question is, how old were you when you were first involved directly in your IEP?

And do you wish you had gotten involved earlier? Is my

question. And I'm going to start -- actually, I guess

you've alluded to this already, Beth, but I will start with you, Beth, with this question.

>> Elizabeth: I actually had James involved in his IEP meetings starting at probably age 6. I just brought him along with me. And part of it was because I wanted to communicate to him and this really was my impetus in general is the reason I call him king James is I wanted him to know he had worth and his voice mattered. Even if it was sitting around the table and listening, he communicate in the traditional sense.

I wanted him to know that people cared about him and talking about his needs and wanted to make sure that he understand he could have input on that. And also it was an opportunity to



see that I was also advocating for him. So when I had conversations with him in other settings he could see how I was taking that information and bringing it into the meeting.

And also to --

For him to see there would be times to have disagreements and it was safe to be in an environment where there were disagreements. It was okay. It didn't mean people didn't care about him, it just meant they had a different view. It was important that he was involved early on.

>> Alixe: Thank you. Sara, do you want to add in how old you were when you were involved with your first IEP meeting?

>> Sara: I started at age of 13.

>> Alixe: Age of 13.

>> Sara: Honestly, I would have.

>> Alixe: Thank you. That is honest and appreciate that.

Lynn, do you have comments when Maggie was involved?

>> Lynn: Maggie, the best of my recollection started attempting later, more like the transition age of 14 in Massachusetts. She was somewhat reluctant participant. Just having her go to the meetings is where we started. I think in retrospect if we had done more prepaving. If I had kind of Had my kind of sense of my role and the place of self determination in her life, had that kind of understanding clear front and center earlier on, it would have looked different.



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Here we are. I am actually curious, I don't know if it's appropriate to ask another panelist but I would love to hear from Beth about how she got it so soon. Like -- because Maggie goes to a school where she's -- where people are thinking and talking all the time about

You know, supporting her to her adult life.

And they were the ones that prompt the her to start going to the IEP meetings. But all that advance work to kind of -- for her to gain confidence to understand what her role might be has come along later.

>> Elizabeth: It is an interesting question. For me I think a lot was the way I was raised. I grew up at a time when we were coming out of the civil rights movement and I remember my father coming to the school literally on a weekly basis because we were the minority in the community. There was a lot I was taught about education

Beginning and how important it was to have one and how important it was to position ourselves to be literate and to be able to engage in the democratic process. And of course to really understand That we do have a voice in that. And that was something that was really important for me to transfer to my own son. And to my daughter. She is another one who has her challenges as well.



But it really was early on.

Okay, well, I'm not going to be here one day and he's got to be able to fly on his own. And he's got some significant challenges which means we are going to have to get started very early on to make this happen for him.

>> Lynn: Thank you.

>> Alixe: Mary Abby, could you let me know when you started attending meetings, your meetings?

>> Mary Abby: I was actually 14. And at the time I think there was a mixture of feelings. I think I was originally like it's going to be a boring meeting. You know. But it was very informative. And I think prior to going to that meeting I wanted to at 12, 13, I was asking like, when you are a kid you are thinking oh my gosh, all of these adults are talking about me. I don't know what they are saying about me. And I'm just in class. I want to know what they are saying. I think at that age I didn't know this but looking back, I wanted to have a voice there.

But I was told I wasn't allowed to because I don't any if it was state rules. I'm in Rhode Island. So I don't know if it was that. But I was told I had to wait until I was 14 and that's when I was able to get involved.

>> Alixe: Thank you. And Miso, when were you first involved in



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your IEP meetings?

>> Miso: Sure, I'm happy to answer this question. So when my family migrated to the U.S. I had turned 13. And it was not even a question that I -- like it was -- I don't know. My parents just brought me there. So I remember my first IEP meeting in the U.S. very, very vividly. It was not great to be honest, but it was an experience that shapes what I wanted -- it shaped my aspirations and as I -- after that experience I just -- like there was no question like should I go or not go? And I think as I became more fluent in English and my parents English language kind of -- it took much longer time for them to get used to the American systems. So I think in part at one point I started -- my parents started almost kind of handing things off to me. And I'm really -- I do wish that it wasn't that way, but I think it worked in favor

For me to become more fierce and stronger advocate in person.

>> Alixe: Thank you, Miso. So we have a follow up question. A number of you have talked about when you wanted to be attending your meeting, right? And there are a couple of questions that have come through about how do we make meetings so that students it wouldn't attend? If students themselves are reluctant. And what about if parents are not quite thinking that their students should be



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attending? What are the first steps to make the meetings be as important and as student centered as they should be? Aim going to start.

I'm going to turn to Emily because I think you had some experience with a broad range of meetings. And other panelists can jump in.

>> Emily: So in terms of parents not quite feeling ready. One experience that I had was working -- I worked specifically with a team of educators in newburyport. And we were working to make the transition to students directing their own meetings. And it was interesting. Because when we started the teachers thought they were doing that.

And as the process went along they realized wait a minute, we are not so much. In terms of getting parents on board we shared along the way with the parents about your student has been practicing, preparing speaking for their IEP meeting. They are developing confidence. You know.

We are so proud of their abilities in this area. So parents could actually get the message and be so proud of their child and already it's sort of the prepaving. Already thinking in their mind. Oh wow, my child is going to speak at their IEP meeting. So it helped for parents to switch their thinking To fearful of the kid being in there for whatever reasons, wow,



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my child has been preparing.
They are practiced. They are
ready. I think that is helpful.
And the first part you asked
about is the child feeling safe
and want to go be there. I
think it is so on us. The other
practitioners, teachers in the
meeting. We have to think of
creating a safe space. And I
always say
To anyone and I do this with
role play with teachers. I have
it be like your own meeting.
And imagine you listening to
everybody talk about you. How
would that feel? Like how is
this going to be a safe space?
An empowering space? A place
where you are so excited and you
couldn't wait to get to it?
Imagine you couldn't wait to get
to your IEP meeting because you
are going to hear from your team
about all of these great
qualities and potential they
saw. You would want to come to
the meeting and everybody would
want to be there. And I think
we have to shift how we think of
IEPs to make it an empowering
safe space that is exciting.
Because it's about the next
year, the future. If it's that
kind of a space being created a
student will feel safe. And if
they don't feel safe it is
something for the team to
reflect and say wait a minute.
What vibe are we giving? What
are we giving and we need to
create that safe space and
empowered space.
>> Mary Abby: Do I mind if I



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jump in? I have a similar thought. I agree 100%. I think that as a student I was kind of hesitant to join in. Although I was excited, I was nervous. Because I was thinking they are going to be talking about me. So I don't know if I want to hear all of these things they are going to say about me, because they may be talking about weaknesses or things I'm struggling with and that's awkward for a 14-year-old to be hearing. But I think that it really does -- things do need to change based on how these meetings are run. Because a lot of the times they are talking about your weaknesses and a lot of students hear that but they don't hear all the positive progress that they are making and all the good things they are doing. So in order to make it supportive and welcoming I think a big part has to be like, oh, student X made a lot of progress in his writing. Here's an example of really good writing he did. It helps make the student feel like what I'm doing matters. And these -- they are really noticing that I am making progress. So I just wanted to share that. A lot of the problems with students not wanting to go is a lot of hesitation that they are going to hear a lot of negative things including a lot of positive things would help. And having a discussion with the student about the



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Different topics that will be discussed

Meeting. For example, oh, we are going to talk about your reading ability it is getting better.

And there are some troubles and this is what we will be suggesting. Things like that so they are aware those will be topics and it won't be a surprise to them as well.

>> Elizabeth: Can I piggyback on that too? There are lots of things we need to prepare our students for these experiences.

And it is not an all or nothing.

I think of it as an incremental process. There are lots of ways for students to participate in the process, right? They may not want to come to the meeting right now. But we don't let them off the hook of them still providing input that could help us to be able to make the plans we need to make. I sat down with parents and students and bargained with the student. Do you think you can stand us for 10 minutes? How about 10 minutes? And when I talk with the team

It's like we have him for 10 minutes. We have to make it really exciting.

Let's talk about something they are excited about so they want to be there and they see they are being heard. And see people are excited about their presence there as well. And that they want to actually do things to support them. So you know, you



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do it from both sides of the table. But really and you are starting out at 6 years of age. No kid is going to sit for an entire meeting at 6 years of age. But they can come in and say I hate reading because of this and I like math because of that. That's a great place to start. And as time goes on they get more accustomed to sitting around the table and talking about what they want and what they need and struggle with. Because the teams are open to it.

And you give them a piece of responsibility. A piece of that puzzle. That's how over time it's like anything else we do in the IEP. We want them to do it with one or two props and eventually we want them to initiate it completely on their own.

All of those things could be built upon over time. And if you do them in discrete chunks, over time it become as full picture and they are able to engage in that skill actively on their own. But let's not all of a sudden at age 14 say okay, you are required to be at this meeting. The kid is like what has been going on the last six years?

Really helping them get used to the idea and having pieces of it. It could be a letter, it could be an email. It could be a video. Whatever way it helps give that input. Give them the opportunities to explore the



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ways that work FWOR them work for them. We do the same thing. We find ways to communicate easier and advocate for. Give them what methodology works for them. And give them praise if they are successful. And debrief with them later if they feel frustrated or if they feel it didn't go well. What is it about? What do you think was happening when that person said that to you? Because at this point you are incorporating other skills like problem solving and things like that. All things down the road will be critical skills for them.

>> Lynn: So I wanted to say that the IEP meeting that Emily and Beth are describing sound to me like the person centered planning meeting that I found to be so constructive. And I think it addresses what Mary Abby was talking about how it comes from a place -- it is structured in a place of empowerment and working from strengths. And you know, Even if a team is celebrating accomplishments, the whole premise of an IEP is that You are arguing for another year of services. So there is a default mode Of thinking in terms of deficits or what is more meaningful to students and the more they can find their voice.

And I wanted to put in a plug for snacks. Because I think snacks go a long way toward making things appealing.

>> Elizabeth: Are you suggesting



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an edible reinforcement?

>> Alixe: Sara, did you have something that you wanted to at?

We are getting close to the end of our time and I want to make sure that you have an opportunity to get in a final word here.

>> Sara: I agree.

>> Alixe: Thank you. And there has been such affirmation in the chat as many people have seen. There are a lot of comment that is have come through. Some just the panelists so we will make sure some of this gets shared as well. As Miso mentioned, there are all the resources that have come through will be included in the content that we put together and post on the NCAPPS.acl.gov website in a couple of weeks.

>> I should also say we've seen a number of questions come through which we are just not going to have time for in this current webinar. And what we will do though and we have done in prior webinars is we ask our panelists to give us a little bit more of their time to review questions that have come through. That we didn't get a chance to get to. And provide some written responses. So that actually is a way to have a little more thoughtful commentary on some of the questions that we haven't gotten to.

And just to wet your appetite there are a couple will of things -- a question that had come through that I might even



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put and give people a couple of minutes to answer before we go to our evaluation questions.

And that is that many times when people are doing IEP meetings, there is a focus only on formal supports and less emphasis on formal or nonpaid supports. And I would love to put this question to you. We are going to squeeze in one more question if we can. If you can talk about

How you have managed or your thoughts on including informal supports as part of student directed, person centered planning for students?

>> Emily: I would say from my experience I'm working with a lot of kid that are getting jobs. And or want to get jobs. And so often they are in the community and they have a job like a formal support. But once they get hired these natural supports happen. And so I think it's so beautiful then when you are in the meeting you are talking about oh yeah, so and so's co-worker is assisting them with that. Or they have a friend they have lunch with. It's so natural and it should be natural. Because like any of us that have co-workers that help us in different ways. So from my perspective it's like that natural unfolding when a person is out there in the world where they can make friends and have natural supports just happen. Like we do.

>> Alixe:



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>> Elizabeth: I would like to add. I think often when we think of people with disabilities and relationships in general, we tend to only think of the caregiver role or formal support role and we don't think about true genuine relationships. And nor do we necessarily take the time to think about how do we support our loved ones with disabilities to have reciprocal relationships? A lot of us are good to remember the email card for people for their birthdays or acknowledging a holiday or things like that. How do you help people with disabilities to know they need to engage in those kinds of relationships? We have to be careful not to define what a relationship is. Just because our relationship looks a different way doesn't mean their relationships look the same way. So what may not feel like it's meaningful because they don't do the same sorts of things or communicate the same sorts of things, doesn't mean these are not meaningful relationship that is are important to them. When we look at all of the people with students with disabilities interact with those are varying levels relationships that could be built upon. If you see sun that gets your kid, explore how -- if you see someone that gets your kid, let's find a way to explore, be more engaged on a personal



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level. I over the years have had personal care assistants that have helped me manage my son's needs. He is a maximum assistance type of guy. But there were several over time that literally were with me for six, seven, eight, nine, years that almost became like a big brother to him. And so as I'm thinking in terms of long term in the days I'm not going to be here, those kind of relationships become critical. Because I need to know there is someone that knows him from a medical standpoint but knows him as a person. Who respects him as an individual. Understands the kinds of things that make him laugh and understand the kind of things that piss him off. And will not only support him that way but will advocate for him and really cause other people around them to respect him and recognize those things. So I think make sure we are putting goals in the IEP and natural opportunities for them to explore different types of relationships. Because not everything is about the support worker. There are other types of relationships out there that are so important for them to have that.

>> Alixe: Such important things to note. Thank you, Elizabeth. We are just getting to the point where we are going to have to continue collecting all of this information in chat. I saw somebody asking whether chat



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will be saved. Yes, it will be. That is part of what we make available. And with that I'm going to again thank each and every one of our panelists. This was an incredibly engaging conversation for me personally as an occupational therapist and practitioner and worked in many schools and sat in many IEP's good and bad. It makes me think for student directed IEPs. With that, I'm going to ask Connor to pull up our real-time evaluation questions. And with this we will thank you and ask all attendees to respond to this. This is very helpful. With the real-time evaluation questions, there are more than two questions. You can scroll down using the Gray bar that is in your box. And we really appreciate hearing from you because we will be doing future webinars on this on future topics. Please keep in touch with us at NCAPPS. We really do listen to our community. We are most interested in doing things that are useful and supportive to the community that NCAPPS is part of. And as Bevin said we are interested in making person centered thinking planning and practice a reality in people's lives and to do that we to be listening. So Thank you very much everyone. We will be continuing to be in touch. Please follow us on Facebook. If you are not doing that already. And twitter. We will -- if I can remember how to



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put those handles in the chat we
will do that right now.
And we look forward to hearing
from you.