HEATHER THEOBALD:
Welcome everybody! 2022 to the webinar. So good to see some familiar faces. We are so happy to have Kathy Powell with us and we will get right to her and just a moment. There are a few little housekeeping items Rose and I are going to talk about. Then we are also going to hand it over and let her introduce herself in the subject, then we will end with some housekeeping. And a survey.

I did want to let you know we are recording this webinar. It will be placed in the same website that you registered. So, I will provide that link. Underneath the title, under 'transition tab' in the titles that is where you will find this recording â€“ if you would like to find people to share it with or if there is something you would like to go back and review, for whatever reason we have this recorded.

So, I am Heather and we also want to remind you I am going to be manning the chat along with my colleague, rose to see if it has any questions or anything we can add to support Kathy while she is concentrating on the content. Because it is recording, we ask if there is anything brought up about any students it is in person first language and because it is going on our website, not to be specific with students names or any detail or information. Kathy is available, she will give her information that you can talk off the webinar for any of those type of items.

ROSE ROTH:
I am Roseann Roth and I am at the public schools and I'm very happy to be with you today. I did want to remind you it is being recorded. Even if it wasn't, we would like you to stay needed while they are presenting and if you have any questions or comments feel free to put them in the chat and we will definitely address them. We want you to be aware we have our ASL interpreters and also our closed captions. Please utilize those services if you need them. We are ready to go.

Kathy is going to present unsupported decision-making that goes along with transition IEP's. So, even though we had that as the title, it is going to be supporting decision-making but it really does address the IEP as well for Kathy, with that being said, are you ready to go?

KATHY POWELL:
Exactly. To add it to what she said, it is all transition we will talk about self-determination, skill building, with efforts to help parents understand their role as well with helping students with independence, and resiliency. Very important skills that can be added as goals on transition IEP and where we can start as early as elementary school. And talking about what that might look like. Both at home and at school. OK?

ROSE ROTH:
Kathy, I did not introduce you.

KATHY POWELL:
My name is Kathy Powell and I am the program director for popping which is a program that stands for parents offering parents information and networking and is part of the Family Network on Disabilities. I will talk about our program in the next coming of slides. So, today is Substitute Decision-Making to Supported Decision-Making â€“ with an emphasis on supported decision-making. When we think of our students, even more significant â€“ disabilities we often think about what others can do for them, including decision-making. My focus will be on helping families understand decision-making as a tool that will allow people with disabilities to retain more of a decision-making capacity by choosing supporters, it could be family members, it could be community members, and we will into that as well.

So, welcome! Again, I am the program director for Poppin which covers 37 counties in North Florida which stretches across the counties all the way to Brevard County. We have parent trainers that are sprinkled along the region that are available to take phone calls from parents interested in information and resources are meant special education. They want to better understand individuals with disability education act, the law that covers special education. We are happy to help unravel anything you might not understand, if you have a sticking point with your child's school or IEP, we are there to help to help you get back to a collaborative relationship with your child's school.

So, we are a nonprofit Family Network on Disabilities is a 501(c)(3). Which means we do not work for local, state, or federal agencies. We are funded by the US Department of Education. The office of special education programs. In part, as well as funding from the US Department of Health. All of those services are free because they fall under our grant. We are one of three in Florida statewide parent training information centres which stands for PTI. There is popping in North Florida, PSN, and PEN, and essential and a south border. As well as family star which is our family to family health information Centre which helps families understand health services for children that might have -- might be more medically fragile. We are family driven. We were founded in 1985 around the kitchen table, parents gather together trying to figure out how to better understand special education for their children.

We are a national network for individuals of all ages who might be at risk, have disabilities or special needs and their families. One thing I like to share about FND that is unique is the majority of our board members, staff, and field staff are family members of persons with disability.

One thing we are not is we do not act as attorneys, doctors, or mental health professionals. So, any of the information we share is not legal or medical advice. What we do is share information, resources and support for you and your family. And research-based. And always encouraging collaboration with schools and agencies. Let's get started.

As I shared, today we will learn the difference between substitute decision-making and supportive decision-making and I will provide examples of how an individual can achieve supported decision-making. Let's start with what substitute decision-making is.

Basically, it is a person who makes decisions on someone else's behalf. If they are not able to make those decisions themselves. Understand substitute decision-making is a model. It looks at a person's decision-making capacity. And to give consent, and sign contracts, etc.

Are they understanding relevant information or consequences of a decision? Are they acting voluntarily, or (Indiscernible)? And are they communicating their decisions? So, who is driving that decision-making here?

It may start out as an informal arrangement involving family members or friends. Her other supporters. A family might find it morphs into a more formal, preemptive arrangement into submitting future loss of legal capacity with some temporary proxies or power of attorney. And finally, a formal arrangement where a court appoints authority or state appointed trustee, guardian, advocate to make decisions on the individual's behalf.

I am sure many of you have heard of guardianship, or conservatorship and until recently â€“ that has really been seen by many as the primary remedy for situations when a person's capacity is in question. Now, I will not go into the continuum of all the different options for youth as they turn 18. We do have a presentation coming up in February. Specific to guardianship and alternatives that will be provided by our CEO, Richard Labelle who is also an attorney and very versed in this. That will be our part two, under that transition Academy. So, I hope you can tune in because it's a great presentation and he's very knowledgeable in this.

So, substitute decision-making, these decisions can be about a person's medical decisions, like went to see a doctor, living arrangements, where to live, what they are doing during the day, as well as financial decisions. How to spend money.

Now, supported decision-making is an emerging â€“ nationally recognized alternative to adult guardianship. It may provide another possibility thinking about, and managing decision-making. Through which people with disabilities are able to use friends, and family members and professionals to help them understand the situation first, and make choices. So that they make their own decisions.

And the starting point compared it to substitute decision-making is not a test of capacity. It is a presumption that every human being is communicating all the time, and this communication will include their preferences. Preferences can be built up into expressions of choice, and into formal decisions. We will talk about how that might look early, and how parents can be involved in helping them learn that process.

You know, from this perspective, where someone lands on continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices. So, I have spoken about my son, Sam, and used him as examples. I have his permission. We discussed what I can discuss about Sam and he is very happy to share.

So, I have shared we have done various kinds of assessments, informal â€“ functional assessments, learning assessments, reinforcement assessments, learning, and career inventories. All kinds of things. You can find these online, you can Google these, they are all over the place. If used those as our starting point and they can help examine where a person is in their ability to make decisions, but not as a form to decide whether or not he needs more formal supports, but to look at it as a starting place of what he may still need to learn.

The best place to start is in high school, and looking at that transition IEP and looking at the goals. Making sure that the goals match need. So, adding specific goals around independence, and finding ways that they can learn to self advocate are great areas of life to add to teaching those skills. Or finding appropriate supports.

So, what does that look like? We start with person centred, and this means the decision-making process is centred around a person and their needs and wants. It is important we start to empower our youth. This is where I have been talking about transferring those advocacy skills that as parents we have learned, now, it is time to teach them at the level they can start to learn. To learn different ways they can start using their voice.

Only providing supports were needed. Supported decision-making, you know, a person may only need supports in some areas, not all areas. A person may, you know, for example â€“ they may find an area such as taking transportation, or living independently, but may need help with managing finances. You are kind of working backwards, so you are looking at their needs are, and figuring out those supports that will help them get there.

So, supported decision-making is helping them lead in decision-making processes. Again, what that looks like for an individual with disabilities, it is individual to each child or youth. It goes back to empowerment and empowerment incurs when control or power is passed to an individual, so that person leads the decision-making process and allowing their thoughts, and ideas, and views to be heard.

Now, that again... it varies. Deciding involves having a choice. Sometimes having a choice in decision-making cannot be viewed simply in one way. There is even a continuum for choice that I have read. It is broken down into four, independent choice, supported choice, substitute choice, and no choice. So, wherever you envision your youth right now... try moving them up that ladder. OK? One route for developing supported decision-making is the use of choice charts. I have a few links I will add the presentation. As well as some other resources, and links to some national websites that speak more on supported decision-making. This is really kind of an overview.

Last is better quality of life and studies have shown people that use what is called self-determination, making choices for themselves and having more autonomy, they feel more control of their lives and therefore have a better quality of life. Multiple studies have shown people with greater self-determination are more independent, more integrated in their communities, they are healthier and better able to recognize these strategies.

The kinds of supports, we think about the big things. What are the persons goals? What does the person need to reach those goals? What is in the person's way for teaching those goals? You start looking at who can help and how. You may want to consider asking those questions for several life areas, like the ones listed on this slide. You see financial, and medical, employment, independent living skills, and school related advice, and personal care.

It is a way for an adult with a disability to use their decision-makers to help them understand the issues, and choices, they also ask questions of them and receive explanations in a language he/she understands and then they can communicate their decisions to others.

Now, to help in better understanding who should be on supported decision-making teams, you might want to begin by asking the person that needs these supports. And ask yourself, who shares the joys of this person? And who is driven by a like purpose? Who does the person connect with? So, for example, my son has a part-time job working very limited hours at a thrift store. He is very well connected with that new family, he calls them his second family. He enjoys going, and he enjoys the back-and-forth communication. He has new friends.

So, his boss is very invested in him, and trying to help them learn how to navigate the cash register, and putting things on racks and helping to move furniture. So, just in conversations with things he is interested in, they have been talking about how else he can help Sam develop skills outside of that job.

So, that might be someone I would add as a team member to our supported decision-making plan. Think about who else can meet a person's needs. He may need to look at people who are not currently participating in their life, if they are talking about their interests, their special interests, and they have not quite developed a connection to it yet. How can you go about making that decision?

I talk about Sam and his ideas being very fluid, so at one time he was very interested in creating necklaces, think I shared in the last presentation â€“ the essential oil necklaces, he wanted to make them out of plastic. We connected because of that. We connected him to art therapy, with someone starting to work with him in creating models out of clay. Helping him connect at some level, you know, obviously we were not getting ready to write a business plan, and market it, yeah. Just something that started to connect him to an interest, to show that his ideas and dreams had value.

So, you know, decision-making arrangements takes many forms. With a family member, or someone in the community, you know, that appointed a decision-maker, they can control some aspects if needed. They can monitor, but not control. Or they can be there to give advice. Across, basically across all these different life events.

Remember â€“ supported decision-making is the approach for assisting individuals with a choice. And providing them help. To help them with anything that might be difficult to make decisions on, giving them options, hopping them through that process. Either by a particular group, or significant other, or special person that you and that person have decided would be a good fit.

Substitute decision-making is taking a lot of that control away, and that person is making decisions for the person with disabilities. OK?

A guy that might be able to help you, as you think about who might be appropriate, here is some more points. First and foremost, someone that is willing to go on that journey. Of implementing supported decision-making. Also, are they available long-term? We know there will be changes to the team through the years, but you know, someone you can anticipate will be around for a little while. Someone that is obviously trustworthy, and honest that understands you can change your mind, the person with disability can change their mind.

Also acknowledging expertise where it is. If the parent has that expertise and wants to, you know, be heard as well, as well as the person with disability. That person may have knowledge in a particular area we are seeking to include in that supported decision-making agreement.

And focusing on their will and preference. As well as being open to novel ideas, flexible. You know, Sam changes his mind on what he wants to be when he grows up, just like any youth might. I have an older son that has changed what he wants his major to be a couple of times already. Give time to consider those options.

Also, they are respectful of your family's culture. That they are able to create a safe, emotional environment that they understand if a youth has a hard time regulating emotions, they are able to talk that person through their choices. And they are able to communicate in different ways whether it be talking, or writing. Just because a person does not have full control of language, it does not mean they are not given to getting. So, finding a way that can best communicate with that youth with disabilities.

Also, they have links to good information and resources, they are well-connected. As well as understanding resources for those with special needs. They also learn to keep their boundaries. We talked about supporting positive risk-taking, and also one thing that I thought was important to add was, you know, the world today requires digital literacy... in that the person is well-versed in that to help that youth with disabilities navigate.

So, think about as a parent ... Where your youth is right now. How you can move them along this continuum, in school. Scheduling precludes opportunity for choice but there may still be opportunities to choose the order, or timing of activities. Where to take a break, or even allow them to discuss their likes or dislikes, strengths and weaknesses, goals and desires. That is all part of that transition IEP to get to those goals, especially the career goals for what they want to do post secondary, and independent skills.

All of that is called self-determination. All of that is part of those transition services which are starting as early as 12. When you try to think about what that early transition would look like at age 12, this is where we are talking about helping them with communication skills, and building new skills to talk about their disability, talk about their challenges, and their needs. What is going to get them to the next step. Those are those measurable academic, and career goals for their post school outcomes.

Before I dive into some examples of activities, let's spend a couple of moments reflecting on our own decision-making. What decisions have you made so far today? We make so many, lots of small, and bigger decisions. What to wear, what to eat, how to get to your destination, you know, are you going to open up your emails first? Are you going to work on an activity?

Think about what it would look like if someone else made those decisions for you. That you will not have your cup of coffee in the morning, you will have it an hour later. Sometimes you make a bad decision or a mistake. But what happens then? We learn from it. We want to provide youth opportunities to learn from any little mistake. And through making decisions, we also learn about ourselves, others, and the world. At times, we do involve others in decisions. We all get help from friends, or family members. We get advice when we need to make decisions. You may ask a brother, you know, for accounting advice. Or financial advice, or maybe our friend who might be a doctor to understand some medical jargon, you know, all kinds of advice that we are constantly asking for.

That is what we hope supported decision-making can look like for youth with special needs. Where you can help your child with this process, you are part of this team and the team you help him or her build should be up to speed on that person's current support and service. This is where you can share what you are already doing at home. Both at school and at home. This will help the team understand what is available to help the person, and maybe identify some missing supports to seek out. And to include us in meaningful activities, look at medical needs, and look at living arrangements.

Living independently, even with supports involves many skills. Starting with the most basic, it's about having your daily living skills which includes grooming and hygiene. Maintaining, which we are working very hard on. Anybody that has youth will attest keeping the bathroom clean is living skills on their own to learn. Maintaining personal safety, knowing how to take care of yourself. These skills, most of us learn over time at home or at school and they provide the foundation for future learning about what it takes to live independently. Some of our youth may need to learn them more directly. Some may learn from others. It depends on the individual.

Building this into an IEP â€“ we talked about this, using the IEP meeting to advocate your child's IEP includes goals focused on gaining daily living skills if needed. Or self-determination skills, and self advocacy skills if needed. And practising the skills at home, so that your son or daughter learns over time to do tasks such as laundry, dishes, or cleaning.

The ability to compare options and how that might look written into an IEP. Helping them learn planning, how to get what done. Prioritizing. Deciding the order of things, and how that should be done. The ability to make decisions, that goes back to choosing options. Support networks â€“ who can help me? Understanding the agency's available that can help in high school, and post. Communication skills, being able to listen and ask questions. You can practice this at IEP meetings, and will play this at home, you can role-play IEP meetings. Teaching assertiveness. Practising their message, and problem solving is a big one. How can they overcome challenges? Breaking those down.

Then it goes choices, again, choices is key to making decisions. Accessing information and support. Goal setting, what do I want and need to change? Last is life discussions. Trying to have those meaningful discussions to develop a shared understanding of a problem. You know, how urgent is an issue? What does this person want, or need? Can anybody else help them understand the issue, or provide information? Sometimes if Sam and I cannot have a meeting of the mind, whether it be a little bit of a miscommunication, a lack of understanding, I will ask someone in his team to discuss that with them. A lot of times he will listen to them because they are not his mom.

They will have better ability of communicating something to him. Using questions to explore and clarify, making clear as far as advocacy issues. And are starting to provide information on self advocacy very early on, and teaching them how to negotiate and debate, I always say negotiate with manners.

Helping them understand about their rights, and the rights of others. Again, we talked about role-playing, possibly role-playing in preparation for meetings or consultations. You can help them, it does not mean you are not involved at all. You can help them prepare documents, and prepare forms, and keep records. You can help them understand how to deal with emotions at a meeting. Expectations. For doctors appointments, helping them take medications as directed, and is seeking medical care when needed. And helping them provide accurate information about their medical conditions, so, helping them speak up for themselves at doctors offices and as you stay in the background. Helping them maintain hygiene and diet.

Post-school plans, career development, helping them understand to apply for adult services, involving them in that process. Accessing services, and supports needed for success in the community. Whether it be job-training, or job shadowing. Maybe enrolling, helping them enrol in a job coaching services. Supported implement programs, vocational rehab is great for that. Helping them understand their Medicaid waiver, if they are enrolled. Or on the waiting list. Or other job ready and social services.

And where to live independently, do they understand what is involved in managing a home? Helping them learn, and recognize when they are being exploited and taken advantage of. Helping them identify different areas that might need to be extra careful, especially around finances. And helping them demonstrate the ability to vote, informed decisions. All kinds of assistance. Teaching them about assistive devices, assistive technology. At home, or in the community.

Transportation. That's a big one in the community. Helping them be as independent as possible. Maybe starting to take public transportation together. Discussing any signs of unhealthy relationships. And of course, making sure they have an emergency plan, writing down emergency numbers, and contacts.

Last is interest. We cannot forget it is important they are able to communicate their interests that might lead them to some very fulfilling leisure activities. It is not all about academics, and career, they have to have that quality of life. So, that's the long and short of this overview. I am going to be adding several links that will take you again to some national resources for supported decision-making, as well as links to various worksheets, that might help start that conversation. Then I will re-share some of those inventory checklists I have used with my son for functional skills, and learning skills, and different career inventories that might start a conversation going at home.

Share collaboratively with your child's school so you can get the most out of that transition IEP for your youth. I will hand it back!

HEATHER THEOBALD:
OK. Thank you so much. I did put in the survey for today's webinar so we may gather information for Kathy and ourselves. I just put in a reminder as Kathy shares resources wherever there is the video, we will also have those links for further â€“ to go back to as well as the video.

So, did we have... Leonard? Did you want to add anything? Did you have any questions, or...?

SPEAKER:
Now, I thought it was a very interesting presentation and I learned a lot. I'm going to that time with my son, and trying to get him prepared for life. It is his second year after the graduation program. So, I have an IEP coming up this next week for him. A transition IEP. So, yeah. This was great!

KATHY POWELL:
Is your son starting to attend these IEP meetings?

SPEAKER:
He has been attending them the whole time.

KATHY POWELL:
Great.

SPEAKER:
(Laughs)

ROSE ROTH:
Kathy, I have a question. I may have missed some of this. When we are talking about the team for supported decision-making, and helping the individual, is there a formality when it comes to paperwork that they should do to have the team members listed?

KATHY POWELL:
There are informal agreements, and I am happy to share some samples.

ROSE ROTH:
OK.

KATHY POWELL:
It is not â€“ like with guardianship, or guardianship advocacy, that obviously goes to the courts. It is very formal. This is more of an agreement that everyone would sign. Just to agree they are all on board, they have the same vision, and they are all willing to stay in that youths life for a period of time. To help them get through what their vision is.

ROSE ROTH:
OK, thank you.

KATHY POWELL:
I will make a note of that.

HEATHER THEOBALD:
That was great. We stopped the recording so anyone that wanted to talk openly, so we got the presentation. That way if Leonard wanted to add anything, or something for just us. So, that would be great. Rose's question was not in there. When we do that, it would be what that was, like...

KATHY POWELL:
I will add that as a resource for sure.

HEATHER THEOBALD:
Thank you.

KATHY POWELL:
I will add several resources.

HEATHER THEOBALD:
Perfect.

ROSE ROTH:
Any other questions or comments?

HEATHER THEOBALD:
Leonard, are you a parent in Brevard or Volusia County?

SPEAKER:
Brevard County.

HEATHER THEOBALD:
OK, great.

ROSE ROTH:
Leonard, you are definitely the next one we will have, the next transition webinar is on February 8. The title of that one has changed as well. It is something you will be interested in. It is planning is crucial â€“ guardianship and alternatives. That also goes right along with the transition, right? The transitioning IEP, getting out there in the adult world when school is done. Right?

So, that would be something you might want to look at as well.

SPEAKER:
OK!

KATHY POWELL:
Yeah, that really looks at the age of majority and it supported decision-making is obviously the goal. We understand every child is different. You may need something more formal. So, you know, our Executive Director of FND is an attorney and he will discuss all of the different options to include guardianship, and even guardianship advocacy which is where some of the rights are taken over by the parent but not all of them. There is a continuum within the formal so it will be good for you to tune into that.

SPEAKER:
OK. Now, I was looking forward to it. I have been looking at the formal guardianship of (Away from mic)

KATHY POWELL:
We have resources of where you can get some at a lower cost. So, for next month, we will make sure we add some of those links.

HEATHER THEOBALD:
That would be great, Kathy. I am really glad we know where that transition part two, the next one is going. I will make sure I share that with Terry here. I know whenever we have our transition fairs, I know that is a very big one that we try to get out to parents. Again, that is not something we are â€“ it is very legal, and experts in.

I know about it, so, that is a great resource we will make sure... I will market it differently now that I know about that. Yeah. We use that in our ICBM meeting, we use that with a group that did â€“ I do not want to say pro bono, but it was based on the ability to pay and different things like that. They would do some different talks. They have not been there for a while so I need to remember what their names were.

KATHY POWELL:
I think Mr Labelle is also going to be talking a little bit on pool trust, for individuals with disabilities. Sometimes parents worry if they have their youth working too much, it would affect their security. So, this is a way to offset that. That is something he can differently share a little bit. A lot of social agencies come into play one's kiddos leave high school. Some parents may not be available, with Social Security, the Medicaid waiver for persons with assisted disabilities, we learned about it very early. I still find parents that I speak to that call me that are looking for community resources and they have not heard of it. There is a waiting list for that, so you want to get your name in there as soon as possible if they qualify.

ROSE ROTH:
OK. Any other comments, or questions? I absolutely am looking forward to February 8 because it's nice to have an attorney speaking about it. It is coming from the horses mouth. So, for understanding of it, I think it will be a great one!

KATHY POWELL:
If you have â€“ if you can create a flyer, or if you would like me to create a flyer so we can get the word out more, I am happy to do that as well. I know you advertise that on the webpage. We have access to our social media pages, so I am happy to advertise it.

HEATHER THEOBALD:
Yeah, we were talking earlier because it still same transition part two, even having that new name, and what we can do to advertise it will already help a lot more.

KATHY POWELL:
OK.

ROSE ROTH:
Patty, you are muted.

PATTY ADAMS:
Already, it sounds like we are done with the official part of the webinar. Unless there are any questions we will let our interpreters and captioner go. Leonard, thank you for joining us.

Live captioning by Ai-Media

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