UMA-B-ICI-LifeCourse in Action – November 8th, 2023

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[Recording In progress].

>> BETH WIKE: Welcome everyone. We are going to take a quick minute to allow everyone to come in, then we will get started. Feel free to use the chat and introduce yourself, say hello. In the chat, you will also find a link for language access. It looks like it is slowing down a little bit. Out of respect for everyone's time, we will go ahead and get started. Feel free to continue using the chat. My name is Beth Wike, I am a training associate with the Institute for community inclusion out of UMass Boston. I have a couple of short housekeeping notes before we get started. First of all, as you will notice, we are in webinar mode. Webinar mode is different than meeting. You are automatically muted, both your microphone and your video. That is due in part to a large turnout, so it keeps things running smoothly. We do encourage and welcome your participation and engagement. Please use the chapter of the presentation with any questions you may have. You will mostly monitor throughout. We are recording this session, this is our third session in the series. Each session is recorded and these will be sent out to everyone that is registered for you should have received an email from the materials for today's session. If you have any trouble accessing those, you can send me a chat directly and we will handle that and take care of that. I think that is it for housekeeping, I will hand over to Ellen to introduce our session.

>> ELLEN KILICARSLAN: Good afternoon everyone and welcome. This is our third Life course in action series for this year. So welcome. Today, I want to introduce Kelia Torres. She is the copresident of mass family and the founder and executive director of connection Latin X, an organization in the western part of the state. Today, she will talk about supportive decision-making and talk about a couple of tools in particular. The integrated support star and making decisions. I will turn it over to Kelia to share everything she knows. She is a brilliant champion of life course.

>> KELIA TORRES: Thank you so much. I will like to start by saying I will like for you if you have questions to put them in the chat. We will have at least 15 minutes on the presentation is done so we can have questions and answers and discuss any concerns. So, we are here to talk about decision-making and empowering people with disabilities and helping their decision-making. So, we are going to be talking about the process of supporting our loved ones with the decision-making to help improve those skills and decision-making goals. How you would like for them and for us, we are also talking about the life course tools. Which ones can be too. We also want to see what happens and how it brings - - for them. So, we have - - we have to understand that we all know that knowledge is power. If it is good for us, we know something can empower us meaning for our loved ones, we need to make the same thing for them. We need to give power to them and know what their rights are based on their needs. It is that, raising the awareness and challenging the discrimination in order to secure that equal opportunity for them to be included. When we do that, we also empower them because we help them by making choices, participating in the decision-making process. That also gives them autonomy and self-determination which is very important. It helps them in many areas. What is the approach (choppy audio) respecting their autonomy and their capacity, even though they have a disability. (choppy audio) They have the same human rights as we do. When we involve them in the decision-making with supports and accommodations, we are making the decisions on our own so we empower them and express a preference to make informed choices. So, how does the decision-making process go? Next. By doing so, we have to involve them (choppy audio) asked them. (choppy audio) Still, there is a way to communicate with them and that is what we have to look into that. Things that we asked to them for instance, tell me more about what makes you comfortable on your own? It could be as simple as they like to bake, the way to be in the community. You have to ask them, what are those decisions that you like to do on your own? Be focused and comfortable and honor them. For instance, in the morning let's say they just say I want to make my breakfast. How can we help you to have the autonomy? Hopefully we can make a schedule or something that can help them to be able to make their own breakfast. Another thing is what sort of decisions do they find challenging? They will (choppy audio) every decision they make and we can help them with those challenges. For instance, it could be medical, it could be money management. It could be as simple as what am I going to do tomorrow? We are going to help them tools whenever they find our challenge, how can we create a plan and break up a support program so the decision can be made on their own as much as possible. Also, we can ask them how can - - decision-making for us. (choppy audio) It could be, I don't want you. I don't want a person to help me. It could be also show me what information (choppy audio) those areas have to really be considered and take into consideration what they are feeling, what they want, what they need. How can we help them communicate and how possible it is for them to express those needs and those questions that they have for this process. In whatever area we are looking for. The other thing is what areas would you like to have more autonomy or control? Let's say for instance all he likes pizza and you just ordered the pizza. But, did he want pizza that day? Not because he likes that, it's what they want in that moment. Let's talk to them (choppy audio) for instance, medical care. He or she will have a certain area for medical care and they will like for you to be involved in a specific medical decision. When they prefer to you to be waiting in the room? Things like that (choppy audio) I am talking about as our mom, but sometimes with my kids it is like that. My kids are young adults, they are 25, but I sometimes I think sure, I just know what they want or what they need. But is it true in reality what they want or need is what I am thinking that it is? Most of the times, let me tell you, it is not. I have to learn to sit down with them and they are very different individuals, but I've got to say hey, let's sit down and go through this. What are your thoughts and what do you want to see? As a result from this area. They are able to tell me. So, having them to tell you in the process and for them to have emotional control of the things they want is very helpful. Not only for help with us as the supporter, but for them and to see them building having those skills. Letting them know that they can make decisions it is very professionally rewarding. Another thing we can ask them is other options to explain whatever situation, more clear. Did you need any kind of support, verbally, written, visual? Those things we have to take into consideration. Most of our loved ones need some sort of visual support. Another thing we have to think and if you need more time to think about is (choppy audio) from us that can help with the process. Next. So, this is a little bit what I think (choppy audio). When it comes to supporting the decision process with the trajectory, I found that establishing clear visuals with what they want and don't want is very important. It leads us to a better understanding of their hope. We can identify that with long-term goals. We assess - - and we can help support the collaboration. In my case, they want to continue (choppy audio) but if I am not there, who else is going to be the person you are going to live with? It helps them see, okay, let's make this plan. I don't want to live outside of home but if I have to, who was my go to with we feel comfortable that I am sure will be doing something for me in the same way my mom will do it? There are things that will not be the same in the future. We need to make this fluid so they can see it with whoever is in their life. It also helps them build that (choppy audio) they can assist from their past life experience, positive or negative, to continue moving forward. It's going to be the same in the next five years. We can manage this to the labels (choppy audio) making decisions.

>> ELLEN KILICARSLAN: Excuse me, Kelia. We can hear you, the volume is good but it is in and out and in and out. I don't know if you want to slow down or whatever suggestion, it sounds in and out. Maybe just slow down? You are not talking that fast. [Laughter].

>> KELIA TORRES: Let me see, I am checking on my system.

>> ELLEN KILICARSLAN: Even that sentence was clear.

>> KELIA TORRES: Let me see. Okay, more questions in this case that we as the supporter need to make. It is how we approach them. We need to be careful not to rush into things when it comes to decision-making and supporting them. They can really at times be overwhelming. You have to think of how things are going to go. He will make sure that the way that we are approaching our loved ones make sense for them and make sense for us as well. We have to respect them, when we are talking to them. We might hear something that we might not like and still, we have to respect that. (choppy audio). Optimum skills and empower them. One of the skills that is very important is asking ourselves in my approaching this person with respect? Someone said breaking up again. It could be my system or my signal, I am so sorry. I apologize for this.

>> ELLEN KILICARSLAN: No problem, just take your time. You are on mute.

>> KELIA TORRES: Can you hear me better now?

>> ELLEN KILICARSLAN: Yes.

>> KELIA TORRES: Okay, now we are good, right? Another thing is, are we providing information clear and accessible? Like what I said before, they might need a visual support or written support. Some visuals or technology. Are we using all those things for them to have the information that we want to provide and the decision that they need to make clear enough and accessible enough for them? Identify and understand options when it comes to making decisions. Are we empowering them enough? By empower them, do they know the pros and cons of things, whatever situation it is? We had to let them understand that every decision comes with responsibilities and actions of things. So are they aware what is involved with those decisions? If we are doing it in a professional setting, we have to be aware of personnel factors that are influencing this as well. We have to anticipate potential outcomes of those decisions. Also, how can be adapt the approach? It is going to change. The person will continue changing and we have to adapt to those changes. Next please. Some of the best practices that I think are useful in assisting the exploration of decision-making is the tool. I am only using the first two pages, but I'm only using the first one. Most of the family that I have been working with and myself personally, these are the areas where believe the decisions are heavy. We want to make sure we collaborate with them and ask them how much of the support they need. If you ask for instance, can I decide if if and where I want to go they can answer, I don't know. You will note that they need some service support. I happen to have with my daughter nonverbal. I help her to make the decision that if you want to go to the movies or the park, I provide her options. I know by using technology with her where she wants to go. That's all she does. So we know, that opportunity for them to express themselves in making that decision. You will know whether they can do it independently or some sort of support, or if someone has to make the decision for them. Regardless of, I will say I don't use the most restrictive which is making the decision for myself, because I have found that there is always a way to communicate. Whether it is a simple gesture with a little card, there are always ways for individuals with a disability to communicate. We have to find those ways. We have to give them the autonomy to make those decisions in a very respectful way. We have to foster a person centered approach. We had to provide the accessible tools and simplify the information for them. Sometimes too much is not necessarily good. When you use simple communication for them and a concise language, that helps them to make a better choice of decisions. Then, you support the information. You have to give them the advantage and disadvantage. Even more people to help you to assist that person in making the decision and whatever the area is spared we also need to facilitate risk assessment and problem solving. On we find when we are planning with them some obstacles, we do not do it ourselves. We involve them. Let sit for example, maybe you want to do something as shopping. Those are the person has a fear of being in a place where there is a lot of people. One option you can say is maybe we can shop at 7:00 a.m. but there is not many people or go at 7:00 p.m. but there is not that much of the people. You are giving the person tools to problem solve and they are able to make a decision from it. Okay, let me see if I can assist them a little bit more and how and if I have to make the decision. Again, trying to make the decision yourself, but this is something that we will have to do. Encourage self reflection. We have to show them when we do those decisions for ourselves, that makes you always feel like good about yourself, right? We want them to have that self-confidence, we want to boost that an increase the assertiveness and them. When we self advocate, that is what we are doing for them. We encourage them to use the personal strength values to make those decisions. We provide emotional support because like I said, sometimes it is not easy. Depending on what kind of decision we are making, it could be emotional. One of the things I have found very difficult is the topic of when mom or dad are not long in life. That is something on how we are going to have to provide emotional support. We want to understand that we have security of course, but if someone decides something that we are not liking, we have to respect that. Some of the things I can think of is something simple like a person might want to smoke or they might want piercings. It could be something more involved, like probably we can talk about maybe gender preference and things like that. We have to be supportive and promote emotional support and talk to them. The pros and cons of whatever decision it is, but ultimately, the decision is that individuals and we have to respect that. Next one. The next one is the integrated support start. We have five areas where we can always add more support to our loved ones. We identify personal strength. Everyone has abilities. Every human being has the capability to do things like communicate the likes and dislikes, the person is good with technology. Persons are awesome with drawing or whatever it is, you can support that person in that area. Who was in their loved one's life that can help them. To be there with them when things are good and hard, this is something very important to explain for us as parents to emphasize it. There is a need for people to be involved to be involved in our loved one's life. People continuing to build good skills and promote independency, to help them go further like to be a boyfriend, or girlfriend, that could be your agencies coordinators. We need to sit down and identify relationships, who are the people that can help me go further. What we need today may not be what we need tomorrow. You may be receiving services that may not be needed in the next three or four months. We have to go through those services. He will help me with what, with money management and my medical care or my health insurance? Who can help me with personal safety? Those areas can be helped through that area. As community services, how are we going to help them make decisions with where they want to go or participate. How are they going to build. For instance, one of the examples it makes in here is about money management. Let's say for instance, maybe he does not like Bank of America. Let's see what they offer, that is another area where you support them when they are making decisions. Is Florence thank near where the person lives rather than Bank of America. Those things might sound silly, but they are important. As simple as something like that to help the person feel very valuable and the self-confidence totally on empowerment is building there. How are we helping them to use the technology to make decisions? It could be nonverbal and some sort of communication device. It could be that a person is, a deaf person needs hearing aids in order to listen and follow people's conversations. If the person wants to work and they need some sort of calendar to know their schedule, right? Or the phone, to contact the transportation but the person use it to go back and forth to places. Things like that, how are we going to implement all those things in their in order for the person to make the decision properly for his or her life. Next one. So, decision-making means empowerment, right? First was decision-making and self advocacy, now is decision-making and empowerment. The process is very overwhelming but also very rewarding. For us, parents and professionals because we see results and me know that after some tweaks and hard work, we are able to finally see how our loved ones have become more empowered and developed - - be active in participation and aligned those decisions with their values. Those advocacy skills have helped them to eliminate those barriers, and they are able to be in the decision process of their life to be a part of that rather than being on the corner, right? By that, we reinforce them with the accommodations. We also see personalized decision-making. It is not only mom or dad or an aunt making the decision, it is him, her and everyone else with them. Tailored to that specific circumstance, the person can make the decision for their life. The theme is being respective. It enhances well-being mentally, emotionally, physically. That gives them strength and makes them feel alive. It is satisfactory. We are helping them to also be well in all areas. Also, systemic change. For the longest time I have always heard that parents are the ones that have to take care of their kids forever and forever. I will take care of my kids forever, but at the same time, sometimes we assist them in saying your child because they have a disability cannot make decisions, talk or do anything. You are that person and it is not like that. The best way you can help them is to make the decision at the standards they can and showing it is possible. Not only for them but for others. That is how we can create those changes. We need to believe in them and we need to see that making an inclusive practice in every environment is not only beneficial for them but also for the society as well. Next? As a key take away, it is safe to say that the support decision-making yet to make inclusive support and create where they feel inclusive and regardless, there are always ways to get them involved. The support them through the trajectory of life and make their life a good life. We have also learned that we have never support options for them. We help them to talk on their own to express on their own by using different approaches for support and technology, relationships with others in the community support sister. They do everything without disabilities because it's worthy of disability. They are still human beings with rights to be respected in society. I hope this is something that was clear enough. If someone has any questions or comments, they are welcome. And thank you for being here.

>> ELLEN KILICARSLAN: Any questions from folks? Kelia, that was great.

>> KELIA TORRES: I was like my nerves! [Laughter].

>> ELLEN KILICARSLAN: Maybe you cover everything really well.

>> KELIA TORRES: Thank you everyone, I see the chat and I appreciate it. I was talking with Ellen and Ingrid before you all got in the webinar and said for me, I am talking with personal experience, this has been very powerful because I have three kids, two of them I am the legal guardian and one of them we are doing support with making decisions. But, it is not only about those areas to say it is legal or this, it's about how can you support your kids, regardless of guardianship or decision-making, to be the person that they are meant to be? To make those decisions, you do not make them for them. You have to find ways to make those choices and learn how to do it and to advocate when something is not right or when they don't like it. When they need something else and for me, having to learn this and implement it has given me that knowledge as a mom that it is possible and also as a professional that I can also help others to gain that so they can implement it with their own kids. Very early, you can start helping them build those skills from a very early age. We do that sometimes without even thinking when we have kids. We say hey, do you want milk now? Do you like this toy? How about the scholar? We are doing it without even realizing your helping them build those skills. Let's continue doing those things and make them feel more independent. I think that is so important at this time like I said, my voice are 25 years old and my daughter is 21. I cannot be more proud of than that even the limitations are even further than that. Disabilities have been to find them. The confidence in themselves because they can do it, it might not be the same way as me and that is okay. We are unique. You do it your way securely of course because we always have to talk about security, but when security is there, everything else is possible. Continue to do it for them so they can gain that and maintain them. I want them to be sure that when that happens, they have what they need in order to continue at their well-deserved.

>> BETH WIKE: We have a question from the chat from Allison. How do you manage family members who dominate conversations about life choices for their child?

>> KELIA TORRES: Can you repeat that again? Well, it is not easy. We practice things we know and as kids, we are the parents. First of all, all children regardless of age, they have their own life and when you feel like you are not agreeing with your kids, you have to see it for me. Whatever decision you are trying to make, it's a safe. We always have to look at the safe. There are times when all of our kids does not look safe, but just like something and go with it. We have to like them to see if it is safe. What good is it going to give you? Try to not make the decision for them. The important part is not to make the decision for them, just provide the tools. Even if it is with questions, you have to understand that they are a human being on their own and you cannot dominate them. That is not what we are here for. This would be chaos. With our kids in our life, it is the same. Let's say you have a client and the family and they say no because he or she wants this or that and I just want this, this is the best and it is not the same. You have the person with questions and kind of make that plan with why do you think this is the best way and not the correct one. Ultimately I will sit always advocate or involve the person asking them is it safe, what do you think is the best? Would you be willing to take a look on this other aspect? Kind of help them to analyze whatever the situation is and make decisions from there. Depending on their age of course, we're talking about a complete adults. It is going to be their choice ultimately independent. One thing I will say, even though my kids make decisions, even the ones, it is not about me. I'm not medically aspect safety wise, - - is not able. Everything else, I include them. Even with doctors, I always say to doctors, talk to him and refer to him. I am here yes, but he is the patient. I have changed that also. In the moment, you really see your responsibility as a mom. You also have to look at it as a human being. We are talking about him, he has the right to know if he is going to have surgery or bloodwork or prescription change, he needs to know that because he is the one that will go through that. Doctors know when we sit, the first hello is for him. Try to help others to change that mind of I am going to make a decision or I just want this regardless of what the person is thinking.

>> INGRID FLORY: If I can add Kelia, that decision-making tool you shared can be helpful in supporting the conversation of let's go through this and look at where your adult child or child is at an you can help the parents remember or recognize that we are capable of. Maybe step back in those decision-making realms because they can make their own decisions and help the parent own in maybe focus in on and do some skill building around.

>> BETH WIKE: I am going to try to unmute Karen who is a question or comment.

>> SPEAKER: Can you hear me? Okay, thank you Mrs. Kelia Torres, that was a beautiful presentation. Thank you for voicing the is such a wonderful way from your own personal experience and stitching it all together for us. From me in particular, I am the parent of three young adults their autism, ADHD, Asperger's accompanied with other issues and disorders. It is a whole combination of things. What I have found primarily is that they are the key person to let us in on how best to serve them. We have to circle again and again and again and deliver on that in the most fruitful way. Among the people that are connecting to my children are a DMH coordinator was a very thoughtful person was very respectful and kind. I will tell you that the day she moves on to a different position, I will be the first to cry. It looks that the capability of people who sometimes have chosen the right job to do and deliver upon it. If any of my children have a fascinating connection to someone, whether that person makes them feel very comfortable and there is no refusal of engagement, I must say that I sometimes feel a little selfish because I wish I had some of that for me too growing up. There were moments when I had a little bit of a crisis and difficulty. Then again, it is wonderful empowerment and I really love having listened to you today, thank you all.

>> KELIA TORRES: Thank you so much, Karen. It was very nice to hear from you. Our kids are always going to have some if that is going to be close. We have to find out who are they? It could be a case coordinator were affirmed, it can be an auntie. Whoever that person is or those people are, we have to make sure that we include them in this because that is the support and that is what we are looking for. We are looking for our loved ones to have a support system strong enough that they feel confident and going to the person and saying hey, I need to make this decision. I do not feel comfortable doing it on my own, help me please. Or, it could be someone where you as a parent can go to that support and say I need assistance with this. We need to make a decision and I know he or she is not capable of doing it on their own or might need a little different point of view to get things together. That is what this is about, to build a network for them so they can be involved and active in that process. At the same time, teaching them to see how it is done and how he or she is never going to be alone doing this.

>> BETH WIKE: We have a question in the chat from Katrina. What advice do you have for a parent about how their who may never have verbal language? What are the number one or two things I can do to respect her community and empower her.

>> KELIA TORRES: First of all, I will say that there is a movie, it was one of the movies that my kids looked at and say never say never appeared I was told that my son was never going to be able to communicate because he is deaf. The told me because of his cerebral palsy, he is not going to be able to do sign language. So, I was devastated to say the least, but regardless, I taught him American sign language. I taught him how to speak. He uses his hearing aids. We speak to him, but we also use technology. We also have an iPad with communication programs. We have a speech device that he can use on his own for communication. To this day, he speaks. For us, the family we understand him. For other people, he will make himself hear. He will talk the way in no way that he has to incorporate everything, but his message will get across. What I did is first of all assume confidence all the way. I never allowed any diagnosis to shut down the possibility of my kid becoming his potential to never be distinguished at all. I will say continue. Continue believing that he or she will be able to do it and look for ways. Start planning now on how in this age you can use these tools to build those skills of communication your field. If each. I will say goes are great pictures. It doesn't have to be fancy. When I got to the roof the disability, there was no iPad. I took a simple notebook that I bought at Walmart, started looking at pictures. I started getting those coupons and was showing every single day, this is Brad, this is milk, building a vocabulary for them. The penny on where your child is that the age and stage, build up from there but never give up. You as a parent to look also for support. You need support as well, because you are starting in an area where it is difficult and communication is so important. Start looking for support that can help you to build the strength an alternative and things like that. Definitely, the tools will help you a lot for that.

>> BETH WIKE: I am so glad we are engaging. I am looking through the chat, I don't know if I see anything. The recording will be shared and all of the materials will be shared. Generally, later this afternoon, if not by tomorrow. When I share the recording, it will bring you to the recordings of the other sections as well, I just saw a question about that. We have from Linda and our last few minutes, I don't know if there is a question in there.

>> ELLEN KILICARSLAN: I think she is just sharing.

>> KELIA TORRES: Exactly like she says, never give up. My daughter has Rhett syndrome that is basically, they developed - - and at the age of two, there is a mutation in their DNA that makes them lose the ability to walk, use their hands and talk. It comes with a variety of things like seizures and a bunch of stuff. I will say that my sassy girl who was 21, she came into her life and she was eight years old, we adopted her. She didn't know nothing, not even eye contact by the time she came to our home. Right now, she communicates with eye gaze, she uses her eyes to communicate. She let us know when she's going to have seizures, or she does not feel good. She will argue with whoever does not like what she likes. She has best friend that she texts, she enjoys music and also to navigate through Netflix, YouTube. She tries multiple times to connect with my friends through zoom. She is very functional and everyone in the pastors told me, I do not expect her to do much. Yes, she is in a wheelchair but that is not mean anything. For me, as a medical diagnosis to have something to say for me, she is the serenity and this is an individual that loves anything that anyone at her age will love. Fashion, makeup, she loves Pinterest. It is better than mine. She likes her movies, she is very picky with her movies. She loves wonder woman. She can make requests for those things like I want to see this, I don't like this. When you see that autonomy from them and you ask them, I always ask her this is what you want, what is it that you need? I am purposeful things to her like I know it is not what she wants or needs and she corrects me. I know because I presume the confidence, I think she's a human being, she has rights and she has the right to express what she wants and make decisions. That is what we are looking into everyone else. We have to presume that competence and always involve them and build the skills for them. Her self advocacy skills are really high, trust me. It is good because now I know all the things I have implement it with her are working and she has learned from it and she is now using them for her own benefit and life.

>> BETH WIKE: Thank you.

>> ELLEN KILICARSLAN: This was awesome. Thank you so much.

>> BETH WIKE: That brings us to 1:00, thank you so much everyone.

>> KELIA TORRES: Thank you everyone, have a wonderful afternoon.