UMA-B-ICI-LifeCourse in Action – October 11th, 2023

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[Recording in Progress]

>> BETH WIKE: Welcome everyone. We will allow just a moment as we see folks continue to trickle in. Go ahead and get settled, and we will begin in just a moment. Keeping an eye on folks coming in. Just for the sake of time and I know everyone is busy, we will go ahead and get started. Good afternoon, my name is Beth Wike, I'm a training associate with the Institute for community inclusion out of UMass, Boston. I had a few quick housekeeping notes before we get started. As you all know, we are in webinar mode. As you come to the presentation, you will notice that participant video microphone is muted and will be throughout the presentation. You can utilize the chat feature and we welcome you to do so throughout the presentation so we will monitor the chat. Feel free to jump in there and introduce yourself, ask any questions you may have through the presentation. Throughout the series and we will be recording each and every one of the sessions. If you are registered for the series, you will receive a follow-up email for a link to all those recordings as well as supplemental materials. You should have received all the materials that we are utilizing today so that will be the PowerPoint, handouts as well as the official tools from LifeCourse that we are going to be going about today. I will also be adding those into the chat in case you do not have those handy. They will also be sent back out in the follow-up email. I believe that is it for housekeeping, we will hopefully and right on time. I will hand it over to Ellen who will introduce our series and session today.

>> ELLEN KILICARSLAN: Thank you, Beth. Welcome everyone to LifeCourse in action series, this is our second session of the series we have put together for this year. I would like to introduce today's session. It is going to be on the trajectory and life domain vision tools and really focus on plain language. I'm going to introduce our two presenters. We have Rania Kelly, from past family, she is the cochair there, and we have Rebecca Davis, the director of transition projects at the Federation for children with special needs. I will turn it over to them. Thank you for being here today, both of you.

>> RANIA KELLY: Thank you so much Ellen and everyone for hosting us and allowing us to present today. I think we will start sharing screens. We are just going to get into it. So, Rebecca had approached me because we were going to do an in person event. I don't know Rebecca, why don't you talk about how we started this collaboration?

>> REBECCA DAVIS: Sure, I wanted to thank you. Thank you Ellen and thank you everyone for this opportunity, it is good to his information with you. I am the director of transition products at the Federation, I'm also the mom of a complicated kid who was 17. I was both living with this in my personal life and also my work life and heard about charting life course. I went to the training and became an ambassador. We have a push for youth engagement and we are getting ready to have an in person event as a part of our visions of community complex that happens every March. He wanted to do something with youth because of Covid and youth engagement is important. I was thinking, but has to be a way to take some of these tools that seem deceptively simple but make it simpler in a way we can work with youth, just as a way to start the conversation. Sometimes a good graphic and get you started. I am not sure Rania, that I reach out to you? Rania was already working on this, which was great. She has this gorgeous presentation and was planning on a way of creating something that is a little bit simpler, both for individuals with disabilities, but also for folks where English is not their first language. It was a meeting of the minds except I do not have to make graphics, that was the best part about this.

>> RANIA KELLY: I always forget to mention that I am a mom as well for a 10-year-old autistic, nonspeaking boy who has IBD, and I use these tools all the time, personally for myself and for my son. I really love using these tools with families or individuals with IBD are disabilities. I love visual storytelling making it simple and accessible, it's for all of us, not just people who might have some support needs. Let's go on to the next slide and just get into it. We did include a PDF worksheet. If you have it in front of you, great but if not, no worries. You can look at it later, you can relax and listen. I encourage everyone to use the chat, let's engage and make this a conversation. Unfortunately, I don't know if we mentioned this but Kamisha Heriveaux and Austin collaborated with us because we wanted to use real examples of people who identify as individuals with IBD. Kamisha, this was her speaking partner neither one of them could be here today unfortunately. We centered as part of the presentation around Kamisha and she would talk about herself in the next slide and how she was surrounded by family. This is an image of her and her sister that she wanted to share. Rebecca, do you want to add anything to the slide?

>> REBECCA DAVIS: Sure, I wanted to say that before we started, the importance of having an people help codesign and create content is what we should all be thinking about moving forward. We can talk ask people and they do not have any buy-in, so why should they pay attention? We happen to be lucky enough to so some very fantastic self advocates, youth advocates. Two of those in the state of Massachusetts, we are lucky to have Austin Carr and Kamisha, this obligate content creator for Massachusetts. They were totally willing, and I think they are also ambassadors.

>> RANIA KELLY: Yes, they are.

>> REBECCA DAVIS: They jumped in with both feet and were willing to, they are always willing to share their stories. That is what makes think the most interesting, when you can create something personally. Kamisha and Austin are probably two of the most connected people who have ever seen ever. To be able to see Kamisha and asked her to send the pictures for us so we can show this graphic and introduce this concept visually or she does have a really strong family connection. She has a twin sister and the family and is very connected with her family. She is also out in the community. I don't know if you could tell, but's picture was a picture of Kamisha meeting Mayor - -. She is everywhere at all times. I love that we can model this and use this storytelling to get this point across.

>> RANIA KELLY: On the next part, you can see that this is an interactive workshop presentation we did where Rebecca was walking around using posters and engaging the group, either supporting the group with the worksheets. We take a moment and ask people, let's talk about you individually. It can be you or if you are doing this for someone specifically, who is your family? Who is your community? Sometimes we are very limited in who we see. Our community is larger than we think it is an Rebecca, do you want to expand on that?

>> RANIA KELLY: Restarted this in a general lesson plan as a group activity first. You have a big white board poster paper, then we sort of do it as a group. I give an example but as a group, who would you say? That sort of warms people up. They might drop the idea of my mom or my dad and you could talk about friends or family that you have chosen. You can put that on there. You start brainstorming a little bit and then you can go to okay now, you have done this, why do we take a look at what you have in front of you? We did have scribes available if people are having difficulty writing. You can write stuff down. There are all kinds of ways you can do this. If you're dealing with folks that wanted to use pictures, there are certainly ways to do that. You are going to have to know your audience. Starting with the group activity and preplanning of who will be in the room if you can, so you can support them the best way possible.

>> RANIA KELLY: Whatever you like about the worksheet is that it simplifies the tools and it is one thing at a time I can make it less overwhelming. At this point, we going to figuring out what you want and what you do not want. Next slide, please. This is often. He is amazing, he really knows what he wants and does not want. He kind of took over at this point and we focused on wages you want to go with this life? What doesn't he want? Next slide, please.

>> REBECCA DAVIS: I can say that when you are talking to young people and approaching postsecondary transition, a lot of parents say - - can they tell you what they don't want? I bet as the mother of two teenage girls, I hear a lot about what they don't want, but they are right up there telling me. You are trying to start the conversation. You can see that by simplifying it like this, we do not mention the word trajectory. This is what you want and this is what you don't want. Introducing the in a way that these are important conversations to have. It is not a silly thing to think about these things and to take time in your life to think about what you want is a great way to start the plan your life. This is a great way to model in a simple, but direct we.

>> RANIA KELLY: The group was really engaged at that point. They all knew exactly what they were doing. Once Austin talk through this point, we talked about what you do want. Pictures are a wonderful way to communicate this. I feel like you could do it quicker. You send an image and they understand what you are saying in a way where it would take longer to describe it. Also, it's wonderful where communication is inferior using visual tools, expressing themselves through pictures. That helps my son. It is a wonderful way to engage and give people more excited. It is not to be photos of themselves, it could be dreams of what they want. Rebecca, do you want to add anything?

>> REBECCA DAVIS: It started off as a group activity and was simple as drawing two lines on the group of white poster paper stuck on the wall. They have different color sticky notes and we talked about how the straight line is what you do not want. What you do want is the line going up. We asked folks to write three different things for each category and they can come up and shared that was really engaging. They had help, we had extra hands to help if necessary. But, you can do in many different kinds of ways. You can drive have pictures cut out, do it all kinds of ways. They then went up and put them on the poster board. It was just kinda fascinating to see. This was a group of 20 young people do not know each other before, and he started to see some patterns. Everybody wants friends, they just want to have a really good friends. Nobody wants to be board. The fact that boredom came across over and over again really stuck with me. This was a really nice way of giving folks the chance to present themselves in a way that was nonthreatening. It was within a group and we can talk about things together. Once we do that again, we made it a personal activity.

>> RANIA KELLY: I love the chat. This is me, how do you deal with what you want or do not want when you are confronted with a nonverbal person? Were any of the young people they are nonverbal? None of the people there were nonverbal, however my beautiful presentation on how to do the charting life course with people where communication is a barrier. That is my life. Usually, when I sit in on presentations, people are dealing with people who can communicate and can verbally or in written ways access that. I feel like that's longer and if you're interested, I can do the presentation in the future. There is a way and I do elevate my son's a voice and mission people respect his voice. Photos are wonderful way to do it, that is a whole presentation within itself. We can get into it next time.

>> REBECCA DAVIS: We are parents and will have to provide more support. I always try to put my daughter Eliza at the center, but I also have to nudge myself to allow her to take chances and allow her to get to know her and connect to the community where she might feel a little bit because that's not the worst thing in the world. It's hard when they are nonverbal. Communication, trying to have straightforward communication is what we are focused on.

>> RANIA KELLY: There are wonderful hacks to find out what a person does not speak - - I often tell people if my son hurt himself and no one was there to see it, I would have no idea what happened. But, I am still able to figure out what he wants. I will give one example, can we go back one slide? In the worksheet, this is a worksheet about identifying what you want and what you don't want. I always say that I want him to be happy. I can tell you, he is the happiest person I know in my life, the happiest. One of the ways, I want to have Harvey you of the community. I often check his YouTube history. I said that he was obsessed with horses. He filters through obsessions with the most recent one was horses. I signed him up for horseback riding lessons. He runs up, leaps on the horse and everyone is so impressed. He is part of the stable community. He has friends. It has been wonderful. This is what it is, how did I know what he wanted? There are ways to figure out what someone who struggles with communication wants. Next slide.

>> REBECCA DAVIS: We can do a whole presentation on that.

>> RANIA KELLY: I do have a whole presentation centered around my son and how I do this because I had to figure it out and I am sure you have too. That is our next project. These are wonderful tools. I cannot express to you, some people really love these tools as is. There is a young man who I will be presenting with next week who every time I ask him questions, he was say to me what do you mean? He is on the spectrum. There was no way I could ask him a question and he could understand it and answer me. This is a kid who has a college degree. Very intelligent, very capable, but could not answer questions about what he wanted and did not want. I literally just gave him these worksheets as is. He filled them out, me and my mom, his mother and I were shocked. We finally tapped into his mind and it was beautiful. But for others, a lot of people, this tool may be a little hard to use. There is a lot of space to write in and you may feel overwhelming because of all the categories. That is why we created this worksheet. Rebecca, do you want to add anything, or should we get into it?

>> REBECCA DAVIS: I think that is good.

>> RANIA KELLY: Next slide, please. We really want to get people excited. This is all about graphics. To have a full happy life, we get to plan for each part. It is not hard, we are going to start today. We won't get through all the five categories, but you have started to plan your life and we celebrate it at the end which is really exciting. Let's get to the next slide.

>> REBECCA DAVIS: Hang on, let me say something. We tried to do things with less language and more pictures. People feel less stressed. Families are already stressed and overwhelmed at the prospect of whatever postsecondary transition is. You put those big long work on it and people are like oh no. There are so many topics and facets of it. I love this presentation because I love this direct approach. Rania has done this wonderful job of taking this great information and simplifying it. This helps the families. This definitely helps me. It certainly would help young people, I would think so, we have broken it up. Postsecondary transition, if we can say anything, and the one thing I love about this whole process of charting the life course ambassador or using the tools, you do not have to be an ambassador, just knowing about it, it helps introduce the idea that this is a process. Especially for families were starting it, you get kind of these, like you are a deer in the head lights. You are not going to learn it in one conference, you're not going to learn in one webinar. This is a process of helping watch your young person to as independent and meaningful of a life as possible. Even starting to shift those gears a little bit in terms of what that means.

>> RANIA KELLY: I love the reality, because it is all our reality.

>> REBECCA DAVIS: You will have a lot of questions and our people to ask. When we separated like this, I feel like it is a nice, direct way of getting that grand scheme.

>> RANIA KELLY: During the workshop, we tackled each domain individually. This is directly from the worksheet, but again, we were isolating them so they were more digestible and less overwhelming. Daily life and employment, what do you want to do during the day? What kind of job would you like? Rebecca, why don't you go on with this part.

>> REBECCA DAVIS: If there were advocates or family members, we want to see you folks want to put things in the chat in terms of daily life and employment. I can tell you that some research came out last year, it's a version of exceptional parent marketing that shows one of the highest indicators for successful employment for youth with disabilities after high school as if they have some kind of job experience in high school. When you think of job, it is not have to be a paying job. It can be volunteering or working at your school. If we broaden our minds about what those ideas are as well and the more we get them connected and busy with more opportunities, the more success they will have afterwards. There advocates were listening, I would like to know what kind of high school jobs you have. I can tell you my first high school job, I was a pool attendant. I was a pool attendant for two years in the summertime. It was really gross I figured out I do not want to be a pool attendant so I can knock that off my list.

>> RANIA KELLY: I want to say two examples. The system was to be a fireman you will think they can be a fireman, there is a way to be a part of that community to support that work. There is no reason to limit them. We should challenge ourselves to be creative. My second thing that I like to do is use myself as an example. I have changed careers three or four times. I went to school originally for engineering and ended up switching to the arts, worked as a graphic designer and went back to school for architecture. I worked as an architect, then started working for an environmental engineering firm. Now, I'm shifting focus again. To see that you need to decide now and figure out life at this point, I am still changing careers.

>> REBECCA DAVIS: It is important to have these conversations. I love that someone worked construction with his father. Maria's son is doing an internship at a local restaurant. My son worked in the athletic department as an intern and loved it. The young lady was a bagger and cashier through high school and college. Community newspaper deliverer, shout people get up before school starts.

>> RANIA KELLY: Marine worked at a local farm, that is amazing.

>> REBECCA DAVIS: Danielle did doggy daycare. I could do the job today. If I could get insurance, I would do that. I was talking to folks at MRC about a program in the asked the question about how many people get their first job with support from the parents or a family friend? Everybody in that room raised their hand. I think it is important to remember that perhaps there are systems in place and when we can use them. But, it is not mean that we as parents do not have ample opportunity. Is your best friend a florist and can they work in the flower shop? Did you like books and can go hang out the librarian on Saturdays? It's about creative thinking.

>> RANIA KELLY: Yes, the slides in the workshop are distributed but if you do not get them, we can follow-up.

>> BETH WIKE: They will be sent out, I will respond in the chat.

>> REBECCA DAVIS: Right on. Chambermaid and the waitress.

>> RANIA KELLY: I love this, but we need to go on. There are so many wonderful resources if you go to the charting the LifeCourse websites. One of the sheets is really quite remarkable. It has all these options of traditional ideas for daily life and employment in every category, then more creative options. I don't know Rebecca, do you want to add anything? I don't want to linger too long.

>> REBECCA DAVIS: It's important, I will love to hear other people have done as they have gone through the transition in life. This is the way the conversations can happen at home. Are you talking about your first job? Do they know you wanted to be an opera singer but ended up being a veterinarian? You don't see it as failure, I got more information and it did not work out for you me these are processes.

>> RANIA KELLY: Okay, next slide please. I love working with Rebecca, she is amazing.

>> REBECCA DAVIS: Bonnie Thompson gave free ice cream.

>> RANIA KELLY: Again, it almost feels like an incomplete presentation because we did this with Austin and Kamisha. They were very vocal about what they wanted and did not want. Austin said I want to continue my radio hosting on a virtual podcast or be a peer mentor for students with disabilities going through special education and college experiences, or something with advocacy. In school, he is in school getting his human services certificate. They are both such remarkable people, they are my heroes. Do you want to add anything, Rebecca?

>> REBECCA DAVIS: If you can get your young person to engage in you are sitting around having these conversations, what a great thing it is to say yes, it is so great and why? Why do you want to be a peer mentor and do something with advocacy? Instead of the kids down and says I want to be a zookeeper, I work with the young man at Perkins school for the blind and said he wanted to be a zookeeper. We said that is so great, we hooked him up with the volunteer ship over the summer. He studied tigers and was going to be the guy outside the Tiger pen and tell people facts. We took him and over time he realized that one, zookeepers need to work outside he did not like working outside and two, tigers smell bad. He was not fond of the smell. But, he learned more from having the opportunity of having to say yes and how are we going to get that for you? He learned more from that experience that if we set down with them and said dude, zookeeper, really? We keep that information, buyback. It helped him home animals working with that he liked because he was not going to have to smell them and worked outside. This is the process we have for everybody. This is how you get to the really good stuff, when people are relaxed and know you are interested in hearing what you have to say. But we are doing now you're telling us through the chat, it is wonderful. We cannot talk forever going to each of the domains and that is wonderful. Depending on the time you have, maybe is 20 minutes a week and you explore, or maybe you set it up where it's a series of things but you do not pick it all in, and one hour and not pick it up yet. There are all kinds of ways to present this.

>> RANIA KELLY: Up next slide. The next domain is community living, it is very easy. We really like to talk about cultural differences. I come from a very intergenerational family. We live in intergenerational households. Usually when I hear I want to live on my own, I don't live on my own. I live with my mom and my son. Everyone sees where they want to live as they see independence and who they want to live with, it is very individualistic. There are no right or wrong answers and it always changes. Rebecca, would you like to add?

>> REBECCA DAVIS: We talk about this all the time whenever we are planning a presentation. There are cultural differences and you want to respect that. I always say to help your young person to be as independent as possible because I do not want to assume what works for me and my family will work for yours. I did try to approach all of these conversations with tell me more. Tell me more about that. That's great, can you tell me more about that? But some sort of unravel these thoughts in real time. How many times do we get to do that? How many times are people listening to what we have to say and not trying to guide the conversation somewhere? I went to my daughter's open house a couple of weeks ago and I know they care about her, but it made me so sad. She was being guided all the there always guiding her and I said to myself and how exhausting it must be to come home in the afternoon after you have been handled all day? It was a good reminder to always give her, her voice. Even if I don't always agree with that she is saying for me to say it's time. Anytime you can have an open conversation with someone and listen to her we want to go, people feel that and have a genuine connection. They feel respected.

>> RANIA KELLY: You are so amazing. She blows my mind. Community living, this is all material from charting the life course. Part of the reason we are asking you to write in the comment is people inspire people. I asked these questions of everyone in my son's life. His teachers, his age, people see different sides of him that I don't see. The more conversations you have, the better and Rebecca, do you want to add anything?

>> REBECCA DAVIS: No, it is self-explanatory. We are modeling - - this conversation you want to have.

>> RANIA KELLY: Again to my which often was here to speak for himself but he had mentioned, I would like to live in an in law apartment or with my brother and/or a roommate with the PCA care support and support persons with my family next door and nearby. I dream of accessible housing and easy commute in my community. I remember everyone is talking about accessibility with transportation every level. Rebecca, did you want to add anything?

>> REBECCA DAVIS: Not really. This is a good place for a young person, we get a lot of this because in the call to get the Federation, Colby did a number on everyone. We won't really know for a long time to understand how teenagers were impacted. Everyone, whether they have a diagnosis or not. But the anxiety levels, I remember talking to community professors who say everyone who came in that freshman year right after Covid, self identify as having anxiety issues and that was the conversation they had sometimes it is hard when you are anxious and didn't want to think about things or start the conversation. Again, this is where the joy of what don't you want to come into play. I know with my older daughter was in college, when she turned 18, she told me that my services were no longer needed, but I am paying for college so she had to deal with that. She did not want to live with us. Like you said, there is an age. The idea of saying live with your mom and dad until you are grown up, some kids are like heck no. Let's figure out what the options are. Anyway you can have these conversations and exploring options. Nothing has to be decided today, or within six months or a year, but we have to start to think about it.

>> RANIA KELLY: 100%. As we mentioned in our individual experience, that always changes and is okay. Then social and spirituality. How will I be with friends and had fun activities? How will I be a part of my community? Of course, this was all around a lot of friendships and relationships. I even told my sister the other day because she was talking about a teenager who just started dating, I think about my son was only 10 who has IBD, having romantic relationships. Why is that off the table? I don't know if Rebecca wants to chime in.

>> REBECCA DAVIS: Charting the LifeCourse is good for everyone. There is not a person who cannot sit down with these tools within this framework and take a look at their lives and trying to figure out that if something is not working with them, take a look at what are the challenges and how are there ways I can work things out? I just wanted to reiterate that. We found two things to have friends wants to be poor. You get out of the world. Sometimes we get so busy thinking of things and there are a lot of things to think about, but having a chance to bring it back to what is important for them, that will be the first place that you start. It was a profoundly interesting conversation we had with our young folks at large.

>> RANIA KELLY: In the chat, someone wrote my son has a scenario where we have a lot of land - - have no sidewalk, even though it is the main street in our town. I am in town member and working on the sidewalk piece. I also have contacts. This is why it is important to be thinking about this now. There are now biplanes and sidewalks being built on streets around me. I am an active member of my town. Every community meeting, I am part of the town commission of disability. The active with the building commissions, the zoning commissions, all of that. Make your town accessible. Work with the businesses to employ our loved ones. You have to be active to make this happen. Do not let anything limit you. I love that people are doing that. Next slide. Again, we had the traditional and creative options. Sorry everyone, I am losing my voice. I think it is allergies.

>> REBECCA DAVIS: Me too. Marla says something that goes out to my mom's heart, how do you encourage friendships instead of just hanging out? We need to do this again with self advocates, we need to have Austin and Kamisha here. Kamisha will tell you about relationships in high school and how she was the manager of the basketball team and how she has had a no holds barred attitude about going up and talking to people. It is hard, when a young person notices that you're trying to be very social and nobody is inviting you to things. I think everyone has had experience in their life. I would love to have some answers. My mom's heart is I want to go fix it. You will have a party and invite everyone. My daughter will say heck no. Please don't do that. I don't know the answer is, but it is a common issue before it is an issue with everyone. It's interesting that you bring up your mother because my mother too. We all go through phases. When you were in school, you have a built in community and built-in activities. When you are out of school, regardless of who you are, whether you have a disability, man, woman, whatever age. We are constantly facing two different parts of our life. My mother's office when her mother passed away. She did not have a romantic interest anymore in her life, she did not have her mother taking up a lot of her caretaking time. All of a sudden, she had nothing. Again mom, what are you interested in? Maybe a bridge. I forced her, she did not want to do this. I signed her up for town recreation programs, which are wonderful. Everyone has a right to access this, even people with disabilities. I signed her up, she did not want me to come up for a bridge class. She has been doing it for three sessions now, she has friends, and I changed her life. This is something I do as well because I struggle. I am a social, outgoing person. It was not built-in. I joined a billiard league, that was my social outlet. Everyone struggles with this, not just people with IBD. We have to use community - - like leagues. I like that it is inside. There are no limits, there are so many different activities. Arts, someone can be part of an artist community. There is no reason why you cannot. It's a struggle for everyone, not just the IBD community. We should open ourselves.

>> REBECCA DAVIS: Is a common issue with teenagers and on social media, everyone was like they're living there best life and studies are showing higher level of anxiety and depression for kid to spend too much time on social media. Why can't that is perfect make life? Also, service, I do not know if anyone is in Worcester or Boston, but there is the epic. Empowering people for inclusive communities. It's a program where young people who are transition age - - a lot of times with my older daughter, I was always encouraging her to volunteer. To see that she can be of service and usually, thank you Katrina, she just put the link. Really, to have them approach it as a way of empowerment. How do I want to make the world a better place? Usually, when you get involved in stuff like that, you'll meet people with similar needs. People who are volunteering, in my opinion, are nicer people. They are out there doing it for a good reason. You might meet some more people. Again, sharing these conversations about times where you felt lonely, I know when I left the nest, my mom started teaching someone to read in the afternoons and she volunteered at a local museum. But, she was modeling for me. I'm taking a check on things that I am interested in and filling out my life. Definitely not easy.

>> RANIA KELLY: I want to encourage any everyone to look at the chat. So many people are put amazing resources like meet up, that's a great one. I also tell people not to be hung up on in person, in person is not for everybody. What if you are medically complex? What if you have social anxiety? What if you are neurodivergent and it makes you anxious to me other people? There are other ways, like gaming. So many virtual communities, I have a lot of friends who are part of these communities and they love it. Let's not judge what community is for people. For some people, community is not in person. For some people, it is virtual. For some people, it is 100% virtual and we are happy with that. We should not judge that. It is what fills her cup and what makes you happy. That is why focusing on the person and person centered planning, if groups make you uncomfortable, why are you forcing the person to do that? How do we build up to the and a way that is meaningful and works for them? You do want to push people a little bit to get out of their comfort zone, like I do with my mother for example. Anyway, we can go on to the next slide. Virtual is not productive for my two autistic children. This could be a whole other topic I feel like. Rebecca, do you want to comment?

>> REBECCA DAVIS: Are you talking about the chat but the chat is only going to the host and panelists so that everyone is seeing that.

>> RANIA KELLY: Is that true?

>> BETH WIKE: Folks have a choice whether they want to send it to everyone or the host and panelists.

>> RANIA KELLY: I apologize, I might have read some that were directly to me.

>> REBECCA DAVIS: I just wanted to make sure it was getting the people.

>> RANIA KELLY: So often, again, he's an amazing young man. I hope people have had the chance to see them present. He again said in my adult life, I will like to form clubs, social and emotional groups. Continue with the local some advocacy group. I would enjoy podcasting for my home office and explore ways to connect virtually. Next slide, healthy living. Will they be healthy? How will I get the help I need to be healthy? Again, I have not come up with this. I have a whole system for my son. When we have medically complex loved ones and ones that need a lot of support like my son, he needs support with everything. This is a big topic for me. I need to come up with the workshop to share what I have come up with. There are so many great ideas exclude that to be another time, I will let Rebecca jump in.

>> REBECCA DAVIS: The healthcare transition, when we are putting together a conference, people have said historically that healthcare transition is an afterthought the truck to plug it in when they can. I talked to our family voices director was a complicated kid and I have a complicated kid. You probably have a complicated kid and you know that your day changes on the time and there is a - -4 those of us who live the people were medically complex, we are forced to deal with on a daily basis. I always say when we are planning the stuff is that when you are good about your healthcare condition or healthcare in general, and put together, nothing else works. All these domains do not work if I'm not getting enough sleep and understand I need a healthy diet or go out of control. We tried to reframe it at the Federation when we are doing our transition conferences. We have one coming up Friday and Saturday. I put healthcare transition is the very first workshop. On Friday morning. I want her to think about it that way. I don't want to be the last thing you were thinking about and then something happens. We can't control everything, but we sure do trial. Katrina said make sure if you child has - - individualized healthcare plan. I am trying to change her frame of mind, - - is a great reference. Have these conversations with their young person. When they see that it is important to you, they will think it is important to them. Will you daughter back at her wisdom teeth pulled out which is supposed to because she is 18 and does it the day before your big conference? She will learn from that. We can remodel this, we try to get them to do what they should be doing. Hopefully they don't fall on their knees too much and you think they get themselves in trouble. The more we can model healthy living and show that it is a priority for us from I think looking forward we are helping everybody.

>> RANIA KELLY: You are on point, I do not know what else to say.

>> REBECCA DAVIS: The whole mental health piece as well. Right now, we're going to the domain so we are giving the experience of two mothers were living, but the mental health piece for all of our children now is so prevalent that having those discussion. They are hard discussions to have. When I became a mom, I was thinking now I have four eyes, two sets of eyes watch me do everything. What am I teaching them to my behavior?

>> RANIA KELLY: Austin's response to this is routine doctor visits. Routine tracking is important to my health because if I don't, I will tighten up and lose mobility. I will work with my adult provider to make sure I stay healthy and try to have good nutrition. Next slide. Safety and security, we are on the fourth want and we have seven minutes. This is a tough one. This is one that is always on our minds, Rebecca, when you talk about this one?

>> REBECCA DAVIS: Again, we are talking about beginning conversations that you will have all the time and learn things as you go on. Some things you will learn to experience is something she will learn from talking to other parents. Some things you will learn from resources. What we talked about a lot only get a chance to discuss this is Internet safety something that gets huge, the Navy people in my generation don't think about as much but really need to an understanding that your digital footprint never disappears. That is a tough one. It's another thing about the idea of having conversations about this stuff when it is not a crisis. They see that is something I think about my adult life. I saw something the other day about - - is a great idea. I know my mom would never have done that because she would've been afraid he would have freaked me out. Then I thought, that is not what we are looking for. We are looking at discussing things that could happen and being ready for them. I highly encourage us all to do that.

>> RANIA KELLY: Amazing. This is all from the LifeCourse worksheet. They give you transitional and creative options. We are almost done and almost out of time. Austin's responses I hope to have a financial account or representative to manage my finances. I will explore a life coach gently manage my life tours. I will work with the PCA and support people to provide transport and community living. This is the last one. Rebecca said you always start with health, actually always start with advocacy and engagement. Especially because my son is nonverbal. Especially because people, I have to really make sure people respect them, listen to them and that they teach them how to listen to them. This is my favorite one. I love to empower everyone whether it is self advocates, family members, is my favorite thing to do. That is why advocacy and engagement is my favorite. Rebecca, take it.

>> REBECCA DAVIS: I have a feeling everyone who is here is probably very good advocacy and engagement were they would not be here for this is a reminder that we have come really far in the past 50 to 60 years. At the Federation, we are looking at, is about to the 50th anniversary of the Federation and the 50th anniversary of - -. I do think that we can never stop trying. We can never stop pushing, because we do have, we love people who have challenges and engagement with the world. We have our own challenges and engaging. If there's something to be done about. I am a big advocate in teaching advocacy and engagement and making sure that you feel like what their opinions are, are important. They should expect the people listen to them and they say yes or no about something and that they have an effect on the world. I think we are fortunate here in Massachusetts because we have so many organizations. A lot of the times when it is so great that we can collaborate. You do not want to duplicate services for duplicate message. If we can all stand behind the same message and say these are our youth and this is my life and I matter, what does that mean? How do we make the world a better place for folks like me? I think again if you are doing that or five a way to include your used. Say let's go to this, is to clean up the beach for advocate to get a crosswalk the one that works for people who are visually impaired, and really help them achieve that so they can see what is involved in stuff like this, it's more than a light on Facebook, or Instagram or Tik-Tok. Investing takes more than 10 to 15 seconds that is our social media. We have nothing else to do, right?

>> RANIA KELLY: We are out of time, but this is how we ended our workshop and this is how we will end it with all of you because it is exciting. You just being here today, you started planning your life for a good life. I want to thank everybody for allowing me and Rebecca to share this, it has been wonderful, thank you.

>> REBECCA DAVIS: If anybody is interested in the transition conference on Friday and Saturday to go to www.FCS and.org. We are doing a day and have conference with youth. You can bring your - - along.

>> BETH WIKE: Thank you everyone for being here today, thank you Rebecca and Rania. We will be sending all the information in a follow-up email, thank you so much.