**[Kristen Dahl]**

Happy Mental Health Awareness Month – May. I hope you are finding ways to take care of your Mental Health this month and always. Welcome to our merge series webinar Accessibility Matters: Neuro-inclusive Cancer Care. Our presenters today are Melissa Levin and Mariana Vetoulis-Acevedo. Melissa Levin is a licensed independent clinical social worker. She's a senior social worker at Dana Farber Cancer Institute and a programmatic specialist for the Neuro-inclusive Oncology Care and Employment empowerment program. She provides supportive psychosocial oncology services to people with intellectual and developmental disabilities or IDD who are facing cancer. She also works on system improvements to remove barriers that produce inequitable cancer outcomes. And her prior roles Melissa provided counseling to transition aged youth at Newton public schools, and worked alongside self-advocates to develop curriculum for youth with IDD and Dr. Jessica Kramer's Youth and Young Adult Empowerment Leadership and Learning Lab. Miss Mariana Vetoulis-Acevedo is a 26 year old bilingual disability advocate. She is a graduate of the Cotting school and Newton public schools where she obtained a high school diploma in 2019. She was admitted to the two year associate degree program in Criminal Justice at Massachusetts Bay Community College in 2019. Mariana has a vision impairment and shares her experience to help other people with disabilities. She currently attends to 3LPlace. Mariana is a community council member for the Pecori funded study, Research Ethics for All. In her role she helped develop a new accessible research ethics training for researchers with developmental disabilities. Mariana’s knowledge and experience have been foundational to the Neuro-inclusive Oncology Care and Empowerment Program at Dana Farber Cancer Institute. Mariana has shared how she learned about and coped with her family's experience with cancer. Mariana’s mom had cancer twice and is now in recovery. Mariana has also worked in the Youth and Young Adult Empowerment Leadership and Learning Lab with Dr. Jessica Kramer and Dr. Ariel Schwartz. She helped with the design, questions, and visuals for the PEDI-PRO app, self-report software for teens and young adults with IDD to share how they do everyday activities at home, school, work, and the community. Mariana also contributed to journal articles and presentations. Mariana’s previous work experiences also includes a Waltham police station, and TJ Maxx. In her free time, Mariana enjoys being and traveling with her family, having delicious dinners, rowing at Community Rowing, Inc., and caring for her plants. My name is [Kristen Dahl]. I'm a program manager at the Human Development Institute at the University of Kentucky. My pronouns are she/her/hers and as a short visual description, I'm a late 40s white female with blonde hair. I'm wearing a black shirt and brown dotted glasses, I have a background with the Human Development Institute logo. On behalf of merge and Human Development Institute, I would like to thank you for taking the time to be here today. The controls are located on the toolbar at the bottom of your zoom window. Please use the chat feature if you have any comments or technical issues and we will do our best to assist you. Please use the Q&A to submit questions for our presenters, we will hold questions for the Q&A towards the end of the webinar. There is a hand raising feature you can choose - use - if you need assistance from the merge team. Other than those presenting the webinar, everyone is muted, and camera access is turned off. You can turn on captions from the Zoom toolbar by clicking the CC button and select the Show subtitles or select to view full transcript. For a running transcript of the captions. You can also change the size of the caption text by selecting subtitle settings. ASL interpreting services are being provided. To access the services on the toolbar, click interpretation and then choose Sign Language channel. A floating window will appear, and you can resize and move this window as needed. You will receive the slides, resources, and link to the recording of today's webinar via email. And the resources will be shared in chat throughout the webinar as well. This webinar will be recorded and will be available on our YouTube channel and the merge website. Your feedback is important to us. When you exit the webinar today an evaluation will appear in your browser. We also will send the evaluation via email, and we ask you to complete the evaluation so we can improve future webinars. The content shared in this webinar are the views and opinions of the presenters and do not necessarily reflect like this of the Administration for Community Living, or the University of Kentucky, and I will now turn it over to Melissa and Mariana.

**[Melissa Levin]**

Thank you so much for such a lovely welcome. We're really honored to be with you today. Let me pull up our slide deck. So, we will be talking about neuro-inclusive oncology care. And I want to first start off by sharing that the topic of cancer can be an emotional one. Please take care of yourself. That may mean taking a break, if needed. That may mean take some breaths, or any self-care that is helpful to you as we discuss this topic. So, we have three goals for our time together. Today, we'll be learning about environmental and systems barriers that contribute to cancer care and the inequities that are experienced by people with IDD. We will be learning about the experiences of people who have both developmental disabilities and cancer. And we will be identifying what are some practice steps if you may be a provider? What are the steps that you may take to increase accessibility and planning and delivering cancer care. So here is our agenda. We'll start off by exploring just a little bit about disability. Mariana will be leading a learning activity for us on what is an environment. We'll then dig into the disability inequities, current and oncology. We'll share a little bit about our program at Dana Farber, the narrow inclusive oncology care and empowerment program. Mariana will then be sharing a few stories with you that have helped her understand cancer and the way that it affected her family. And then we have some action steps that Mariana will be sharing that are for everyone. We have no financial disclosures to share. And we do have a thank you to the CJL foundation for supporting the launch of our program. And consider this to be an adventure. So, we'll be sharing lots of information with you. And on the slides. There are also clickable links, that if at a later time, you want to learn more about a particular topic, feel free to check out the clickable links. And we also have a resource list as well. So, I'd like to share visual with you first. And it's to represent how people are multi-dimensional. And several self-advocates who worked with us on the development of our neuro inclusive program really want me to highlight the multi dimensionality of people with disabilities. I've sat in on a number of merge webinars and practice groups. And I know that in the merge community, we not only get this, but you're honoring. So, when we support people with IDD, it's really important that we both zoom out and see the whole person and the whole person in the context of their environments. And we can also zoom in and zoom in to the multiple identities. And when we talk about multiple, multiple identities, we also want to think about any marginalized identities that people have, or they may be facing repression and compounded repression. So, some of the areas that I'd like to highlight are the communication and the range of communication that people with IBD have, in terms of both expressive and receptive language, and also the way that we all learn. And in a medical setting, there's so much information really, really complex information, we need to think about the strength of the learner, the tools that will help the learner take in this information that's really complicated. These are some aspects for us to consider, as well as intersectionality, race, gender identity, sexual orientation, and more decision making. So, this is an area that we've been spending a lot of time talking with providers about how there are many types of decision making that are used by people with IDD. And that can include being independent decision makers or sole decision making, having supported decision making and having legal guardians in some circumstances. When it comes to independence, independence is such a big and fluid topic. We can need support in some areas and be independent in other areas. And so it's really important to lean into one as independents look like for this person, and not make assumptions, and I encourage all of us, right, some of us on this webinar may identify as a person with a disability may identify as an ally, Ally may identify as a provider, let's all really strive to be aware of any internal biases that we may have, and how these can play out in our interactions with one another. So, I'm pulling up a picture on the screen. And in this picture, there is a person who's using a wheelchair, the person is next to a sign, and the sign has the words weigh in. Everyone welcome. The sign is at the bottom of and pointed in the direction of many stairs, the medical model of disability would perceive a claim that the person in the situation has the impairment. And there's a word bubble here that says her impairment is the problem, they should cure her or give her prosthetics. So, it's focusing on the person and the person needing to be fixed. Now, as we think about the social model of disability, that recognizes that the problem does not exist within the person, the problem is the stairs and a lack of accessibility to all users building a ramp could fix this problem. So, the framing of disability with the respect to the tremendous impact that the environment has really honors the experiences of people with disabilities, and a person with a disability doesn't need to be fixed or cured. It's the environment that impacts the accessibility. That's what we really need to be focusing on. And so, for any providers who are on this call, this framework is so important, because we need to think about what does it mean for there to truly be access to oncology care for people with intellectual and developmental disabilities? How do we truly make oncology care accessible? So, Mari and I are going to tag team this next slide. Ready? So, Mari, can you tell us what are some examples of an environment?

**[Mariana Vetoulis-Acevedo]**

Physical structures and things.

**[Melissa Levin]**

What else?

**[Mariana Vetoulis-Acevedo]**

Sensory: lights, sounds, textures, tastes, and smells. Workflow and processes – directions to follow, order of steps.

**[Melissa Levin]**

And one more right here. Mhm.

**[Mariana Vetoulis-Acevedo]**

People’s communication, expectations, and attitudes.

**[Melissa Levin]**

Absolutely. So, here's some examples of when we think about the environments, and when we're thinking about the environment in a cancer care setting. Here are some examples of it. We also have a few pictures as visual examples. And we would love for everyone on this call to just take a minute or two minutes to answer this next question into the chat and Mariana, what's the question? Yep. [together] What parts of the environment might help or make it harder to get cancer care? So, thinking about the environment, can we all take one or two minutes and share some ideas into the chat of what may help or make it harder for people with disabilities really, for all people to get their cancer care? We're starting to have some ideas about noises, lights and the actual physical structure. The equipment is an accessible transportation Communication Complex turns the imaging being in a really tight, confined space, prejudice about quality of life. Yep. And we will talk about that in a few minutes. Resources Available verbal written visual time, the entries, the exits, audio visual accommodations and all of the ideas that you're putting into that chat. These are exactly what we have been thinking about. Over the last year, as we've been working on the launch of this neuro inclusive program. I also see physician unfamiliarity with IDD. Yeah. So, physician provider training, comfort. Excellent. And feel free to like keep sharing these ideas in the chat as we go misunderstanding about pain. We'll also be talking about pain today. Absolutely. Thank you so much, we're gonna keep moving along. So, we'd like to share some of the research with you on oncology inequities, as compared to patients who do not have intellectual and developmental disabilities. Patients who do have IDD are diagnosed with cancer at later stages, experienced delays with their care. And this is not only a delay, to initially receive a diagnosis or initially have a scan to confirm the diagnosis. We're talking about that all parts of the continuum. people with IDD are given fewer treatment options, have poor pain management, and are dying at higher rates due to cancer. And so there were some comments in the chat that are hinting at some of the barriers that are producing these inequities. But we're going to also dig into it. In a few minutes. I will say that much of the research that I've found regarding this intersection of oncology and developmental disability was conducted within the last few years. This is an area where we need more research. So, thinking future directions, if this is something you're interested in, we need you, we need you for this. And this September, many of you are likely aware that the NIH recognize people with disabilities as a population experiencing health disparities, warranting increased research and attention focusing on this work. So, you know, we need this, we need this now. And we can be leading the way and empowering How are patients with IDD are accessing the healthcare system. So, I'll tell you just a little bit about our program. I'm not going to spend too much time because there's a link that you can click into to check out what we're doing at Dana Farber, we've created a program at Dana Farber that provides specialized care, and that's aimed at improving the outcomes and reducing the distress that often accompanies cancer diagnosis and treatment. And so, we are really focusing on adults, cancer patients who have IBD. And it's multi-pronged. So, we have our work that we do with our providers with our physicians nursing, any staff that has any kind of direct or even indirect involvement. We're providing consultation, we're also exploring this whole idea of the environment, what can we be doing, as a system? What can we be doing in the environment, sensory, physical, attitudinal, etcetera., so that our environment can truly be accessible. And then on an individual level, we spend time building supportive relationships with patients and also their care partners, we can do a lot of work before someone is about to even come through the door to help them feel more comfortable about what they're going to be experiencing. We do a lot of previewing we're about what to expect. And that can include visual aids, creating social stories first, then boards, lots of creativity around this. And then we do supportive individual counseling. And we'll use evidence based techniques and also modify as we need to, so that anyone who's coming in who has a developmental disability and facing cancer as that same access to all parts of physical and psychosocial care. So, I'm going to show you a visual that's in collaboration with our patient family advisory council members. So, we do a lot of work with members of the Dana Farber community who have received their care here, or maybe a care partner. And we've been thinking about these different levels of bear. So, I'd like to share them with you and also levels of considerations. So, at an individual level, we want to the carving out time to really learn about each person and think about their strengths and reflect this to the team so that we're coming in with that strength based perspective. If, and we can start to build some rapport. We also can figure out what are the ways that we can make a therapeutic tool makes sense? Can we figure out their personal interests, their affinities and tie that in? And again, we know that people with disabilities, face oppression, we want to build those relationships help them feel empowered in this journey. With preferences, we also dig in, what are their preferences with communication expressive receptive? How about with learning all this really complicated information? And what are the preferences when it comes to the sensory environment, and we're going to take all that information and put it toward the plan for when the person comes in for treatment with decision making, here's where we've done a lot of work with providers. And I know there was a comment earlier about provider familiarity. There are so many different ways that decision making can look. And so, we try to educate our providers around each unique person and what their decision making is like, are they independent in their decision making? Do they do supported decision making, if they have a legal guardian, still, we want to have the providers speaking directly to the patient, they are that Primary focus. And we want to break through if people do have an assumption that they think a patient needs to have a guardian, and they don't have a guardian. That's not the case. They're independent, they're supportive, we want to break through these assumptions. At an interpersonal level ableism. So, we've been doing staff trainings, raising awareness about ableism, and how this can be conscious unconscious. And it's this form of bias against people with disabilities, where value is assigned to people's bodies and lives. And it's learned from society. It's really like deeply rooted in our medical system. And we want to do some self-checks on this and really raise people's awareness and break through those assumptions. We're doing work with our providers, all of our teams to just build up their capacity, and bring in self-advocates to help with that training. So, communication, the goal is for clear and open communication that really follows the lead of the patient in terms of their communication preferences, and honoring their use of any assistive devices or any tools that may be helpful. There's a resource documents that will be shared out with some examples of the kinds of communication information we ask about, and then share with our providers. self-advocates have done a lot of work on the diagnostic overshadowing piece. And what I mean by this is the assumption making that some providers make when they are overly thinking that the person's developmental disability is the reason why they're having symptoms. Oh, it sounds like you may be overstimulated or that's best to talk about with your psychologist. We’re trying to work on Hey, can you recognize all of me, honor all of me, and that my disability is one part of and not all of me. And when it comes to cancer, and when it comes to early detection, we really got to be attuned to like, what are you noticing in your body? That doesn't feel like what you're used to? Or what's the pain? What's the discomfort, you don't want to just overly attribute can't do that. Really got to dig into it. Pain assessments, I saw a couple people commented on this. This comes up all the time and thinking about do the current assessments that we have in medical settings, are they accurately capturing the experience of someone with IDD? Are they actually accurately capturing if they're having pain or to what extent that they're having pain? And I've had so many self-advocates, who have shared with us that the typical assessments that are used are not representative of their experience of pain and like how can we think more creatively about assessing and documenting a person's experience of pain? And we'll talk a little bit more about that in the next slide. So more of a systems level, and big picture environmental level, electronic health records. So, at Dana Farber, what we've been working on this year is systematically screening for disability identity and accommodations and it's a - it's a choice - so it's self-directed if somebody would like to share, and we recognize that this choice carries some risk with someone sharing their disability identity. So, when someone shares that we really honor it, and we make sure that the providers then know, here's the patient, here's some parts of their identity. Here are the accommodations that they're requesting. Let's make sure that we get this in motion when the person is coming in or advance of their visit. for accessibility, can people be getting into getting out of their rooms? Can they access the full appointment for a full workup? That is really, really important that diagnosis with treatments, you can't have a successful visit if you can't properly evaluate someone because your medical equipment is in excessive wear because someone is not trained in doing that full workup. Sensory overload, light, sound smell all the above? What can we do in our sensory environment? What can we modify so that someone can feel as comfortable as can be when they're in a fast paced setting, like a cancer care setting? With allocated time for appointments can additional time be carved out with patients who need it so they can fully access the information in the appointment, have full clinic workup? etc. For health literacy? When information is provided, like chemo teaching sheets, is the information truly accessible? Is it actionable to a variety of learners? With security, I have been working very closely with them because I learned from our security team that they really want to better understand what might outwardly present as challenging behaviors as a means of communicating discomfort or distress or disconnection, and how self-advocates have share that, you know, oftentimes people will miss perceive if they're trying to engage and coping and they're doing some self-dialoguing or some stimming or pacing, people may miss perceive it. So how do we create environments where people can use their coping tools in a dignified manner with access to quieter spaces or designated what we're working on recalling pacing pathways, designated areas where Hey, go and use it, you need to get your body in motion, you just got some really tough information understandable. And the last piece is coordination with other systems. So, we're thinking about how we collaborate again, when requested and consented by the patient with departments of developmental disabilities, different conditions for the blind, deaf, hard of hearing, that's a trap. I realized that's a lot of information we just shared with you. But really important considerations when we think what can we do as providers or s systems to help make this really overwhelming, scary experience more accessible, and more comfortable. So, in Massachusetts, we call this disability competent care. In other states, I've seen it referred to its disability affirming care or neuro inclusive care. So, lots of ways to call but what we're trying to say is that to make oncology care accessible, we need to be recognizing and treating each individual as a whole person, not a diagnosis or condition, addressing all these different barriers we just went through, that can make it harder for people to access their care. And truly, every single day counts every day counts. So, we want to get timely, successful visits and treatment in place as soon as possible. And that our care is focusing on the support of each person, and really maximizing quality of life. All right, got a bit more information. And then the couple minutes, I'm going to switch up tomorrow. So, what we're doing at Dana Farber, we've called it a neuro inclusive assessment. So, in addition to learning about each person, and what is known as a bio psychosocial assessment, this is to get like a real sense of who the person is and the context of their life. We also want to know the neuro inclusive piece. So again, we talked earlier, we want to know about their communication, expressive and receptive. The use of assistive technology. How that person best learns, how can we as providers present the information in a way that's going to make the most sense to that person? We're going to be aware of the decision making. Definitely personal strengths, always want to emphasize the strengths, the interests really connect on that level. And when it comes to disability identity, and a similar way that we would talk about pronouns we want to get a sense of when we're talking about disability out loud in writing and notes. How do you want us to talk about your disability? Do you prefer that person first or identity first, and we find In that just opening up this conversation is a really, really meaningful one. And it also helps all the providers get on the same page with the language. Well, we'll get in depth on the sensory strengths, likes, dislikes, triggers, and do our very best to honor all that come up with a plan that takes that into consideration. As well as accommodations and strategies. And then the last piece is making sure that we are honoring care partners and supports that the person would like to have included in their medical care, including state agencies. So here are two examples, because our assessment is still in pilot, I don't have the actual visual that I can share with you. But if you would like to check out there are two great health passports, these are not oncology specific, but these really helped inform our programmatic development. So, a shout out to checking out the sun healthcare toolkit and also at a Florida the My Health passport. And then there's another link that you're welcome to click through from the Office of Developmental Primary care. Really, really cool stuff. And these are great tools that you can use again, not only in oncology care, but also in Primary care if someone has an inpatient stay, etc. So, feel free to check that out. When it comes to the sensory sensitivities, I just want to share some of the most commonly initiated also address sensitivities that we've been working on in our program we just launched this past year. So, we are a new program, but we're very active with referrals. And so, the sensory pieces we have been thinking about include pressure when they're coming in for visits. Also for chemotherapy, for radiation, things like weighted blanket, squeeze balls, pain, figuring out what's the best pain scale to really get a sense of what the person is experiencing, numbing spray, also when medications may be needed to help with the addressing the anxiety, for scans during treatment, adjusting the lighting, because those rooms can be so bright, considering the positioning someone's coming in for chemotherapy, we have chairs, we also have beds, what's going to feel best and also incorporating time for movement and making a plan with the nurses if we need to carve out some movement time, as well. Lots of requests around noise and noise reduction. So, we have some different options that we think through as well as having folks bring in noise cancelling headphones providing an amplifier, when needed, when it comes to people thinking about people as support access to a support person, of course, this is this is really challenging when you're coming in and you're getting chemotherapy or radiation. So, let's figure out a plan for the support person if that's helpful, and even calling in if there is some other supports who are not physically in that environment but could be on a call could be listening in. We provide a visual so the pictures of who's who is on the team when that's helpful. And then we do a lot with visual schedules, being able to do the real life pictures where they're going in the hospital who they're meeting with. Okay, so I think Mari and I were gonna go back and forth on these and mix it up a little bit. So, here's some of the questions and concerns that have been raised thus far by patients and our new inclusive program.

**[Mariana Vetoulis-Acevedo]**

What is cancer?

**[Melissa Levin]**

Yeah, what is it? I don't understand why I feel like this. What's happening?

**[Mariana Vetoulis-Acevedo]**

Did I do something wrong?

**[Melissa Levin]**

Yeah, this is a question that comes up a lot and trying to understand like, why, why did I get cancer? What did I do? Will other people catch my cancer? This is also a common question that I get. Oops, let me just move my zoom over to see that next one. Why did I get it? Trying to understand that if I didn't do something wrong, Why? Why do I have this? What is an oncologist cancer doctor? What is a care team? We keep hearing the word care team, what does that mean?

**[Mariana Vetoulis-Acevedo]**

Can I do things like going to work?

**[Melissa Levin]**

Yeah so, if I'm getting chemotherapy or if I’m on a targeted therapy, can I still go to work. Is that okay? I want to talk about something different, not cancer, just needing to take space from talking about it.

**[Mariana Vetoulis-Acevedo]**

What are side effects?

**[Melissa Levin]**

What are side effects? What does that mean? It's scary in the hospital, or it's scary just coming in for an appointment. And why does medication that should help me make me sick? Trying to understand that. It’s supposed to make my cancer go away, but my hair's falling out, or getting really bad stomach aches. Why? What will help me feel better?

**[Mariana Vetoulis-Acevedo]**

Will this last forever?

**[Melissa Levin]**

Yeah, will this last forever? It's confusing the sense of time and not exactly knowing the future, that's really confusing. Did I do something wrong? If my medication doesn't work. Or let's say, I hear this a lot, too. Did I do something wrong? If I get my blood drives taken, and I can't get my chemo today? Because my white blood cell count is too low? Did I do something wrong? Will my cancer go away? So, these are just a sampling of the questions that I've been getting since we rolled out our program. So, I want to talk to you about the therapeutic strategies that we've used thus far. And again, you can think about this like, person by person, there's no one size fits all here. We found that visual aids can be really helpful having stories, having even like a menu of the different coping tools you can use when you're coming in for medical care. And I like to take a real life picture of your tablet, or of your fidget or of your headphones just really make it super generalizable. first and then board, what's going to happen first, what's going to happen second, okay, I'm going to do my scan. And then what comes after that? Roleplay in developing scripts, this has been really helpful for a number of people just playing out what's going to happen when I go in, I get radiation or what's it going to be like, I'm going in and getting chemo or developing a script of how do I share my icky feelings after the chemo went away, and I share this with my doctor. They're wonderful ways to modify CBT to make it accessible to people with IDD. And as some of my patients have called it, we can do brain frames, we can really draw out what am I thinking about? What am I worried about? What's the evidence supporting that? Or what else can I be thinking about in the situation, or maybe it's a table of if this worry, thought pops up? Here's what I can say back to myself. So many cool ways of using art and technology to capture how we're feeling and have some reminders for coping strategies or be using like an anti-stress app or a guided meditation app. Sorry, I got ahead of myself with that one. And when we're doing meditations, again, thinking about sensory preferences. For some people that chiming bill, it's often the meditations and the complete trigger, and the ocean sounds may not be relaxing. So, as we're suggesting any kind of mindfulness or meditation, we want to follow that person's lead, and go with their interests and what makes them feel a sense of soothing. And for the pain piece, and really thinking about this, there's so much work to be done in this area, I share an example of the long Baker faces at the bottom, because this is a really popular skill. But it's not one that works for everybody. It can work well for some people, but others and self-advocates if shared, like what if my face never matches up with the way that these faces match up? Or what if that scale doesn't quite make sense to me? So, we need to think about the pain scales that are recommended. Are they understandable? But are they really capturing that person's experience of pain? If there are visuals, Are they helpful? Or if there aren't visuals? Can we add individuals? And are there any other creative ways to capture a person's experience of pain, maybe it's about something that they love doing and maybe if they're used to doing art for two hours a day, but they're in so much pain that they can't sit or they can't draw? We can take some data on activities they love and typically do at baseline but can't do because of the pain and maybe like that's what we use. So, lots of work to be done. In this domain. I did include one resource that you're welcome to check out and I'm pleased to pass it off to miss Mariana Vetoulis-Acevedo who will be sharing some of her stories with us that have helped her understand cancer and I think, Mari, you're an incredible, you know example of how to make really complicated information makes sense, so I'm gonna stop talking and I'm gonna pass it off.

**[Mariana Vetoulis-Acevedo]**

Learning about cancer: Cancer is a scary word. I felt worried when my mom first told me that she had cancer. I wanted my mom to feel better. I wanted the cancer to go away. I had questions. What is cancer? Do I get it too? How do we make cancer go away? My mom and dad talked to me about cancer. I could always ask questions. I learned why my mom was losing her hair and needed rest. I did things to relax. I spent time with friends.

**[Melissa Levin]**

Did you walk?

**[Mariana Vetoulis-Acevedo]**

I walked. I thought about what I loved like my family, my plants, and my friends.

**[Melissa Levin]**

So next up we're going to show an example of how we can use stories and pictures to support patients with IDD and learning about this in a way that's accessible and meaningful. So, Mariana will teach us how she better understands what cancer is by thinking about it in terms of plants. Since that's one of your special interests.

Thank you.

You're welcome. And here's some real life plants from your home. Alright, you ready Mari?

**[Mariana Vetoulis-Acevedo]**

Plants grow. Plants need sunlight, water, and soil to grow. Some plants don’t need as much water, like a cactus. Some plants need a lot of water. Sometimes plants get sick. Sometimes weeds grow where the plant is trying to grow.

**[Melissa Levin]**

That one is a little hard to see on our Zoom screen. Can you see it now?

**[Mariana Vetoulis-Acevedo]**

Sometimes people get sick when cancer is growing inside of them. Just like plants need care to get healthy, people need care to get better too. Doctors and nurses help take care of people who have cancer. Treatments help people who have cancer. Treatments are like medicine, chemotherapy, radiation, and surgery.

**[Melissa Levin]**

So now we have some action steps for everyone. Okay, you ready Mari? Let’s do it together. It is important that people with disabilities be included in conversations and learn about cancer. It is important that systems and environments make changes so people with disabilities can access their cancer care. And Mari, I think this was your idea for any self-advocates on the call.

**[Mariana Vetoulis-Acevedo]**

It is important to speak up if something feels different in your body or if you feel pain.

**[Melissa Levin]**

Absolutely. Speak up if something feels different. If something feels painful, speak up and however you speak up. And we can make cancer care for people with disabilities more equitable by first acknowledging that Disability Matters every time and everywhere. Okay, so let me pull up this part. So, we are now at our question and answer and also sharing feedback, etc. Time.

**[Kristen Dahl]**

So, if you have questions, if you can put them in the queue and a, and we will read them to Melissa. And I'm gonna I don't see any in there right now, if there's anything else that you wanted to talk about? Well, we give people a minute to put their questions.

**[Melissa Levin]**

Yeah, yeah. So, um, a little bit about the resources. So, we put together some of the organizations and links that we've been using, as we've developed this new program at Dana Farber. And I do find that the organizations are, like, incredibly, incredibly helpful. So if you're thinking about starting a similar program, or you're thinking about this for yourself, or for your own family, I would definitely suggest checking the links out, it is overwhelming to read all the information, and given the topic, so make sure that you're, you're doing it in chunks, and in a way that feels, you know, okay for you because it is an it's definitely a sensitive topic.

**[Kristen Dahl]**

Okay, we do have a question, I did want to say that the link we've been sharing is to a Dropbox folder, which has everything that that is being shared today. So, we've shared that link a few times, and we will also follow it up with email. So, the question is, how receptive have clinicians been to this?

**[Melissa Levin]**

Yeah, it's a great question. So, they have been overwhelmingly positive. And receiving our program. I think that, you know, it's been a mix, there have been people who are like, like champions, people get in. And they may be themselves have a disability or a family member with disability, or they've had patients with disabilities, they truly, truly get it. And then I've also found, there's other groups of providers where when we show the research and the information, they're like, Wow, I haven't thought about it in this way until now. And this is a huge problem and something that we can be working on. I am yet to encounter someone that said, like, No, I don't want to spend the time on a console, or I don't want to spend the time learning about your program or making a referral. Focusing very, very receptive, very much wanting to collaborate. Yeah, great. Thank you.

**[Kristen Dahl]**

And their response to that was, that's terrific.

**[Melissa Levin]**

Yeah, yeah. And certainly, you know, I'm happy that if you are thinking about rolling out something in your setting, and you would like some support doing that our goal has been to really build this out everywhere, because cancer affects people in all parts, not just in Boston. And there, there needs to be more supports for all people with IDD who are facing cancer. So, if you need some kind of a cheerleader advocate, yeah, just reach out.

**[Kristen Dahl]**

And I am glad you are doing this work in cancer care, Euro inclusive care and all areas of health care is needed for better health outcomes. How do you handle payments for the extra time needed?

**[Melissa Levin]**

That's another great question. So, we have not been charging for this extra time. And like at Dana Farber social work is an embedded cost. It's not billed separately. And my role is as a social worker. So, there have not been additional costs to it. I will say one area that I don't know if any one of you on the call is familiar with patient navigation. But what I'm hoping to learn more about is patient navigators because I see that there's a real need for patient navigators for people who have IDD and learning more and more about how the reimbursement works for patient navigators.

**[Kristen Dahl]**

Thanks. Okay, you have a question. Will you be attending the American Academy of developmental medicine and dentistry conference in June?

**[Melissa Levin]**

I am not although this would be a good one for us to get on our radar. I will be at the AAIDD conference in Kentucky. But yeah, no, I thank you for putting that conference on my awareness. Yeah. Anything else that you want to share?

**[Mariana Vetoulis-Acevedo]**

No I don’t have anything!

**[Melissa Levin]**

thank you for your time, Mari.

**[Kristen Dahl]**

I think we've answered all the questions. Janet is also I guess, going to be? Well, we've got a couple more comments. This is fantastic work. Have you worked with patients who may have genetic counseling related to cancer risk, and are eligible for extra screening, but not actually diagnosed with cancer?

**[Melissa Levin]**

This is a great question. And Mari, remember how last month we went to the genetics conference? With Dana Farber? So, there's a lot of work to be done in this genetic counseling world. And I've heard from a lot of families back when I did special education, or a lot of families. I know this came up in your family too where what if the parents has hereditary cancer, and they go through treatment, and then they're thinking about for my child with disabilities, or my child who's now we're going to be an adult and is coming up as high risk? Is the system ready to provide the supports? So, when we met with the, at the genetics conference, who folks in the audience were saying they really hadn't heard of anything like this of like neuro inclusive and the training around the genetic counseling in cancer? So, this is another area where if you're interested in it, we got to get some work done. And I know that it's certainly really high on the minds of parents who have hereditary cancers who are thinking about their next steps. patient navigators are different than family navigators. Yes, there are patient navigators in cancer hospitals, who will help patients make sure they have transportation to and from appointments. They can be like a medical scribe, and appointments, they can help do the physical like navigation in the hospital to make sure they can get from where the blood DRA is scanned through the appointments. And the Developmental Disability Nursing Association is awesome. They were a wonderful help. At the start of our needs assessment, so DDNA, I think we have them linked somewhere in the slide deck, check it out there great. University of Kentucky plan. I'll pass that question off to you and Kristen.

**[Kristen Dahl]**

The University of Kentucky plans to implement a program similar to this, not to my knowledge at this time, but I think there is definitely room for development there and for follow up and that we would, I would love to see that happen. So, I would love to know more about that, to talk more about that. And to get more involvement from the University of Kentucky. You've got several comments. Thank you, sir. Some other shared resources in the chat. Please complete our evaluation, which is in the chat and will show up when you leave the webinar. So, thank you so much, Melissa, and thank you, Mariana. This was a great appreciate you been here. Thank you, everybody.

**[Melissa Levin]**

Thank you all for your time and joining us and please do feel free to be in touch. I'm always looking for people to collaborate on this and, and to help you advocate in your own settings as well. So absolutely. We'd love to hear from you. Take care!