**[Kristen Dahl]**

I'd like to say Happy Disability Pride Month. I hope you are finding ways to celebrate disability culture and inclusion this month and always. And we'd like to welcome you today to our merge series webinar supporting people with IDD through grief and loss. Our presenter today is Karen Harvey PhD, who is a clinician, author and speaker, and Karen has worked in the field of intellectual and developmental disabilities for over 35 years. I'm Kristen Dahl. I'm a program manager at the Human Development Institute at the University of Kentucky. My pronouns are she hers, and as a short visual description, I'm a white female with long blonde hair. I'm wearing a purple shirt, and I have a blue background with the HDI logo. On behalf of merge, I would like you to thank you for taking the time to be here today, and we have a few details to go over. So, your zoom controls are located on the toolbar at the bottom of your zoom window. The Chat feature has been limited to host and our technical assistance team, so please use the chat feature if you have any technical assistance issues, and we will do our best to assist you. Please use the Q and A to submit questions for our presenter. We will hold the questions till the end, but we have a dedicated Q and A time from three to 315 where Karen will answer questions. There is a hand raising feature you can use if you need assistance from the merge team, other than those presenting the webinar, everyone is muted, and camera access is turned off. CART captioning is available for this webinar. You can turn on captions at the Zoom toolbar by clicking the CC button and select Show subtitles or select a new full transcript for a running transcript of the captions. You can also change the size of the caption text by selecting subtitle studies ASL and Spanish interpreting services are provided for this webinar. To access these services on the toolbar, click interpretation, it looks like a little globe icon, and under watch, choose the sign language or Spanish channel, a floating window will appear, and you can resize and move this window as needed. If you choose Spanish interpretation, you will hear the interpretation simultaneously, unless you choose to mute the speaker. If you're watching YouTube, a member of our team is monitoring chat as well. This webinar will include content around grief, loss and the experiences of individuals with intellectual and developmental disabilities, some of the discussion may bring up difficult feelings, so we encourage you to care for your wellbeing throughout the session, a link to today's slides were shared in your reminder email, and we will also share that in chat and send it out after the webinar via email, and we may share some other resources as well. The webinar is being recorded and will be available on our YouTube channel and our merge website. Your feedback is important to us. When you exit the webinar today, an evaluation will appear in your browser, and we will also send this via email. We ask you to complete the evaluation so we can improve future webinars. Questions and comments can be sent to me at kristen.dahl@uky.edu the content shared in this webinar is the views and opinion of the presenter, and do not necessarily reflect those of the Administration for Community Living or the University of Kentucky. I will now turn it over to our presenter. Welcome Karen, and thanks for being here today. Oh, thank

**[Karen Harvey]**

you, Kristen. It's an honor. It really is. I'm so excited to be a part of the series, the merge series, and so grateful to you and the University of Kentucky and the whole team here. And thank you for making things so accessible. We have so many different types of interpreters, interpreters and supporters. Thank you. My name is Karen Harvey. I am an older person who has bright lipstick and smiles a lot, a little bit like a clown. So and I laugh a lot also, well, you can think that, but, and I'm wearing a blue and white dress, so thank you, and welcome everybody, and I'm going to try and be somewhat cheerful for a very difficult topic, because I believe this topic is so important, and I can't tell you how grateful I was when Kristen asked me to present on this I was like, Thank you, because I've been talking a lot about grief, and I believe it's something we don't talk enough about, especially in the world of intellectual and developmental disabilities. So let me share my screen, and we will get started. Started, here we go and slide show. Thank you for your patience with me. Aha, it worked. You know, it's the little things that make you so happy, right? So, supporting people with IDD through grief and loss, the first message I have is the most important, and that is Thank you. Thank you all for being here. Thank you for those who work with folks with IDD. Thank you for those who support people who are supporting folks with IDD, who keep systems going.

**[Karen Harvey]**

Sorry, is there - is there a problem? Am I okay?

[Kristen Dahl]

We don't see your slides. We still can't see -

**[Karen Harvey]**

And I was so excited thinking we did okay. Thank you so much. See, I got too confident. Okay, let's try that again. They think we're gonna have it a computer issue. Now we do okay. Sorry about that, everybody. This is like, welcome to being Karen Harvey, can you see it now?

**[Kristen Dahl]**

We've got it now. There you go, of course.

**[Karen Harvey]**

And I already practiced, but it didn't help me at all. Thank you. This is who I am. Those of you who know me know it's always something. So, thank you for being so playful. Thank you. Everybody is so wonderful, so, and my first slide has the flowers, and it says, Thank you. So, it's not just me saying it. So, thank you so much for all of you who support folks with IDD, family members, staff. For those of you who support the staff, we're going to talk a little bit today about staff as well. I think we have to do that when we talk about grief. This is a really important topic. Thank you for being here. Thank you for doing the work you do. Thank you for caring. Thank you for caring in this field. You know, I feel so privileged. The reality for me is that I get to be with the best people everywhere I go, because the best people in every state, in every county, they're the people who choose to work with folks with IDD, because this is work of the heart, and I'm going to go out on a limb and guess that nobody's doing this for the money, but we know right, that this is incredibly rewarding work. And so, thank you, and thank you for supporting those in the field as well, those of you who are keeping the systems going in all the different ways that you are, I want to thank each one of you from the bottom of my heart. Thank you so much. You are the best people, and you're doing the most important work. Thank you so much. There's a wonderful saying from a Buddhist scholar called Nichiren Daishonin from many years ago, the 1200s and he said unseen virtue brings visible reward. So, I know everybody here, everybody in this webinar, has performed many acts of unseen virtue. Probably you can all just think about the last week and someone that you called to check on, or some little detail that you took care of that nobody else thought of. So much unseen virtue here in the Zoom Room. And I want to deeply, deeply express my appreciation. I wish I could guarantee the visible reward. There's a check in the mail, but there isn't. I lied. So unfortunately, we don't have a lot of that, but we do have good karma. And thank you. Thank you so much. Thank you for being here today. Thank you for caring about this topic, which to me, is one of the most important topics, and thank you again for the work you do. Let's talk about COVID. Nobody's favorite topic, right? But so much grief and loss. And I have to say that grief is trauma, and that's one thing I've come to understand through many years of doing therapy with people with IDD and grief is hard for all of us, right? Nobody gets out of this planet alive, as Jim Morrison said. But also, you know, those who are left living are the ones who really hurt and suffer when we lose those who we loved, and for us, it leaves a hole. But for people with disabilities, when they lose that person, it's a canyon when you have so few people in your life who are unpaid, who value you just for your existence, and whose job it's not to be with you. It's devastating. Through my many years of doing therapy. Be with folks. I've done a lot of grief counseling, and I've taught other therapists to do grief counseling, and we started to put that front and center, and I'm going to talk a lot about that today. I believe that folks deserve and need grief counseling, and it's very important, and often they don't have access. And COVID created so much trauma and so much loss. I went in between variants. I went to North Dakota, to Fargo. That was fun. I was excited to get out of the house, let alone be in Fargo. I'd never been to Fargo before. I watched the movie just to get ready, but it was very different when I came but it was so fun, and I was so excited to see people. I gave a talk. I was a little bit over the top, because for a year and a half, I'd been screaming at a computer with people not even sharing their screens, right? So, I'm like, hello. And so, when I first started giving the talk, I was like, jumping up and down and being way too loud. And then I realized, oh, these are real people, and their bodies are right here, and I better tone it down. But then the most important thing for me, my biggest lesson, was what I did after that talk, I did a workshop, and I was supposed to hold a workshop on how COVID affected folks with IDD. So, I was full of myself. I'm like, well, I know exactly how it's been because I've been doing zoom therapy groups, and I've been doing zoom one on one therapy, and I know everything. Because the only thing you need, you actually need two things to be an expert. Number one, you need to be from out of town, right? That's a requirement. And number two, you need a PowerPoint. I have them both. So I go to this workshop, and one person after another starts coming in, and the folks coming in were folks with disabilities, and they were coming in with their staff, and I was like, oh, oh, oh, okay, the experts are here. The experts are in the house, and it's not me. It's not me. So, I just, we had this large room, and I just opened it up, okay, what have you been through? How are you doing? What's going on? Right? And I passed the mic around, and there was this little guy. His name was Philip, and he raised his hand. We said, I'll tell you how it was. I'll tell you. Well, first thing, he was in a wheelchair. He said, first thing, we couldn't go to the day program. The day program closed. I like going to the day program. I see my friends there. We drink coffee, one cup, one cup only. But we couldn't go anymore, and we couldn't go grocery shopping. Gina had to do it by herself, and we can go bowling. We just sat at home, but we watched movies. It was okay, but then Jimmy got sick, and Jimmy went to the hospital. We had to go to our rooms, and we had to stay in our rooms, and we had to eat in our rooms. That was no good, right? So, he was quarantined and didn't really understand it. 100 explained he was a very smart guy, and then he said, but he came back, and we was okay, but then Bobby got sick, and Bobby went to the hospital, and we was back in our rooms, and we were there in our rooms, eating in our rooms. Couldn't come out, just go the bathroom, that's it. But he came back, and then we could go outside. So, as you remember, then things opened up, and people started walking around outside and doing little bits of activity. So, we would go take walks, and that was good, until Linda got sick. Linda went in the hospital, and we went back in our rooms, and then he shook his head, and he goes, but she never came back. And right at that moment that he said that the staff person sitting next to him burst into tears and started sobbing, and he leaned over, and he's patting her and comforting her, and he's saying, don’t worry, Gina. Don't worry, Gina. She's in heaven. Don't worry. And at the end, you know, I was like, oh my goodness, right? And at the end, I said, okay, who wants to sum this up? You know, we had this wonderful 90 minutes of everybody sharing what they've been through. And Philip raised his hand again, and he took the mic, and he said, Live. Life to the fullest. Wow, thank you, Philip, that's the take home message, isn't it? And that's the take home message with grief, we're still here and we're the living and after that, I when the everything was over, I went and I talked to Philip and Gina, his staff, and Gina's apologizing and wiping her eyes, and I'm so sorry. I'm so sorry. I haven't had a minute to cry. I just had to keep going. We had to keep taking care of everybody. I just felt, wow, this woman is so heroic. And, you know, and Philip, rather than saying, yeah, look at what happened to me. And they didn't explain it to me, he's just there comforting her, and continued to comfort her, I was like, wow, wow. What people went through. We went through this phase of isolation. We first had the fear, right, the terror, then the isolation was so hard on folks. I know a couple of people said to me, now you know what it feels like not to get into the community. And then we had this long period of anxiety, and I believe that we still are experiencing the mental health effects of COVID. There are a lot of folks that I know of in places where I consult and work, and people that I do therapy with who no longer want to return to their day program because they were told at some point that it's dangerous, who no longer want to try to work again. There are a lot of people still self-isolating, and because of this anxiety, I think we will look back at this pandemic and realize that the mental health effects still have gone on and have had a lot of repercussions. And we saw how many staff left right, and we saw the grief. The grief was very impactful. I had the privilege of working and continue to have this privilege with the ARC of Montgomery County, who got a grant to support people with grief, and then they were, they got this grant, and they brought me in to talk to the folks. They brought large, a large group of people in because they had lost so many to COVID, and this was recently, and they said, you know, it took us a while to get that grant, but what we're realizing is that people are still grieving their housemates and their staff, and those whom they lost because they lost folks receiving supports as well as some staff. And we had a big workshop, and we talked about it, and people opened up. One fellow had lost there was a house with four people, three had died of COVID, and then they replaced those three. You know, about a year later, different people came in, and one of those folks died of cancer, and he said, Is it my turn next? Right? It was so tough. And then there was this other fellow in the group, and he was somebody who didn't use many words, maybe, you know, four or five. But he kept saying notebook, and he kept saying notebook, notebook. And everybody was, oh, there he goes again. And I said, well, maybe I have a notebook, you know, I'm looking in my bag for an extra notebook, because I always have notebooks. I love notebooks, you know, little ones, but I couldn't find one. So, I'm like, well, I can give you a paper and pen, and the person running it said, you know what, he already took five pens. Don't give him any more pens. And everybody's kind of just brushing him aside. And then at the very end of our workshop, where everyone was opening up about who they lost, and everybody had someone to talk about. At the very end, the staff said, well, you know why he keeps saying notebook, because his housemate died, and his housemate had a job at Staples, and used to, every now and then, would bring home a notebook for him. So, he's talking about who he lost. When he says notebook, I was like, oh my goodness, right. People are affected, and if we don't really take time with folks and process their grief, it's very difficult for them. A lot of folks don't have a friend they can talk to about who died, and they and we're not training staff to sit down and really listen and process with them about their losses. And folks carry these losses, sometimes for decades, right? It's a reality, and it's one that it's very important to me to talk about. Dr Tony miles, out of University of Georgetown, said bereavement is a public health issue the. So many after COVID, and then it continues where so many people are grieving, right? And this, this goes for the folks receiving supports and for many staff. And then there's the grief and loss due to natural disasters. I first started talking about this and seeing the effects of this when I was doing trainings in Alberta, Canada, and they were describing a number of people whose homes had burned during their fires, and folks who were just totally had total upheaval. So, the loss might not have been a person. Every now and then there are losses of people. We know this Katrina, so many were lost. And there were entire group homes that were ruined, and people, there were some people with disabilities who were lost. So many situations, I'm sure many of you can share, and oftentimes we are all so busy trying to just fix it that people don't have the chance to really process their grief, grief and loss due to their living situation changing, due to upheavals, and sometimes due to actual death. So people really need that, that debriefing, that processing, that support when they go through any kind of disaster so critical, and we're so busy trying to place them and fix things that oftentimes people we don't take care of that piece of things, just in our own situations with all we have to deal with. So, I think we have to look at that moving forward like, how can we help people to process their grief and the pain that it all causes and support them, so every loss has an impact, loved ones, of course, Friends, staff, housemates, coworkers, animals. I believe that many people that I've worked with, and many friends that I have, and people I know grieve the death of their pets just as deeply as they grieve a family member, because they are family members, and the simplex people we work with as well, and then staff turnover, because the reality is that staff turnover creates grief and a sense of loss. Staff turnover is quite a harsh reality in our field, and people grieve their staff. I was contacted by one agency. They said these folks used to be fairly easy to work with. It used to be a fairly easy house, and now they're having many behavioral issues. They're very angry. They keep complaining about their staff. They hate their staff. So, can you work with them? I'm like sure. So, I sit with them and they're all really upset, because they had a house manager who had told them that she would be their friend forever. She would always be in their life. She would always be there for them, and they did all kinds of things together, and she was their friend, is what she said. And she basically set them up, probably without intending to. I've seen this a lot, and then one day she was gone, no phone calls, no nothing. When the staff who came in, they hated, and they turned on each other. They were upset all the time, right? We all know when we're stressed, we sometimes say and do things we don't want to do, but the stress of that loss, that turnover, she didn't die, but she was gone. And this happens a lot to folks, and I think we can't underestimate the effects of turnover in our field and how it affects folks. Now, there's some fallacies with grief, right? There's, there's, I want to address this that Elizabeth Cooper Ross her stages. Many people talk to me, and we still sometimes hear therapists talk about that you have to go through the stages of grieving.

**[Karen Harvey]**

Her book that she wrote, in which she enumerated these stages, was called on death and dying, and it was actually about her work with people who were dying. So, it was about folks who had terminal illnesses and were dying, and these are the stages that they went through. And some of the folks that we support, sadly, are in hospice, are put in hospice, are going through similar stages, where first there's denial, then there's bargaining, right? Okay, God, I'll be good if I can just live five more years. And. Anger, why is this happening to me? Then depression, and then finally, acceptance. But the reality is, when we lose people we love, there is an acceptance. Lucas comes in waves our sorrow. Climb helps. Climb helps so much. Our spiritual beliefs help, right? Many things help, but it's not like we get to a point where, okay, now you're over it. Now there's some distance. Now you've accepted your new normal, but it still can be painful. And then there's always that song or that TV show or that phrase that someone says that makes you remember and makes you miss that person, right? This is all of us. We're human. So, everybody goes through a very different process, not coming to acceptance. And I've heard staff say, oh, your mother died 10 years ago. That was a long time ago. You should be fine. But no, no. Folks who receive supports often grieve much longer than most of us. In very I want to say we all grieve, but in much more intense ways, because their circle is so small, because there are so few people in their life, and it's really important for us to help them expand that circle of people who are unpaid, help folks to have relationships that are real and in those ways heal. So, I went instead to the Mayo Clinic, because they do a lot of research on grief, and they have some wonderful recommendations on dealing with grief in general, but that relates to us and the folks receiving supports. So, number one, they say, give yourself permission to grieve. And this applies to all of us, right? It's okay, and we need to do that with the people we support. It's okay to cry. It's okay if you don't want to do what we usually do, and you just want to stay in your room, or you just want to take a walk, or you don't feel like going on the activities you used to enjoy. It's okay. Give them permission to feel and validate those feelings. So critical your grief is valid. Write a letter to the deceased person. So in grief therapy, that's something I've done, but you don't need to be a therapist to help somebody to do this, because I think all of us have things that we wished we had said to folks who died and may want to say and helping somebody, if they don't write, helping them to talk it out and writing it out for them, writing a letter is very therapeutic journal about positive memories. So, we can help people to do this as well. Tell us your favorite memories. Tell us what, what's your best memory with your mother or your father or that staff or your housemate, and write that down, put it in a journal, and then that person has that talking to someone. I believe it's so wonderful if we can get grief therapy with for folks, really important understanding that those around are affected. So, we can, you know, have a nice session with everybody in the house when somebody in the house dies, where everybody shares their memories and everybody can share, lending a supportive ear to others, and preparing for reoccurring holidays when you know that grief is going to come up. This applies to all of us, right? I have friends that celebrate Father’s Day every year their father died because of COVID, and they go to their father's favorite little fishing area, and they have a little party there, and they remember him every year, every year at his birthday. So, prepare for that. Do things for that. And we can do that with the folks we support. We can do that with the house. We can do that in all kinds of ways. The arc of Baltimore. I worked there for many years, and they had a wonderful ritual. Every year they would do a memorial around Memorial Day, where they would honor all the people that they lost, and that year all the folks receiving supports, right? And we would have pictures and candles, electric candles, right? Fire hazards, and we would invite family, staff, friends, and we would take turns talking about each person, kind of like they do in the Oscars, right? You know, these are the actors who died, and the directors and the and kind of in the. Same way, really helping people to celebrate those lives. And then during COVID, they added staff that had been lost because so many staff had been lost, that really gave people a beautiful communal experience, as well as having memorial services. We think that's so important. So, here's some more tools. Something that I've developed, and we have used, people I've worked with have used it, and I've used it for over 20 years. It is the goodbye book, and it is on my website, and it's free. All my stuff is free because it would be just rude to charge money like that's ridiculous, but the goodbye book has helped so much. It's a very concrete way to help somebody to process a loss. And I'll never forget, I've done it with so many people. And I was thinking, you know, I was thinking yesterday and today about doing this workshop and all the stories that I have of wonderful people and grief work we did together. And I remember this one fellow, and he had lost his mom, and he was very, very close to his mom, and it really devastated him. It just devastated him. And, you know, he was referred to me for grief counseling, and we did the goodbye book together. And it's processing not just that the loss, but it's celebrating who that person was, and celebrating who the person left right, who this individual was, to his mom, to the person who died, because that, I want to always reinforce the fact that your value didn't die with that person. So, we reinforce that, and we talk about the favorite memories, and we chronicle that, and we make a book, and then the person has this concrete book about whoever they lost. So, this guy had this book about his mom. And every time his mom left him, you know, she he was in a residential setting, and she would visit all the time. She was very involved, and she would always say, See you later, alligator. And he would always say, not for a while, crocodile. And I've even heard them say it once. And so, we were doing the book, and the last piece of it is something I would like to say to this person. And he said, see you later, alligator, which was really her line. And he said, I think she's going to answer me. I think they'll say something. So, we see these beautiful moments and people they want that they want to have a space, a safe space, to share about who they lost, to share their grief, to express what they need to express. And they deserve that, and it's so important, right? So, we also did. I started something at the arc. I'm really grateful to the arc. They were of Baltimore. They were able to get funding for what we called the healing center, and we took people who had all kinds of trauma, and we would work with them very intensely from September to June, right? And then people would go on their way. And we had people who were very shut down, didn't want to work, didn't want to volunteer anywhere, didn't want to leave the house, in some cases. And they all would after doing this work. It was so interesting. You know, we did a lot of therapy, we did yoga, we did a drum circle. We had a music therapist come once a week. We did group therapy. And what we found, we did it in three sections. First was working on their trauma, and we had people with all different types of trauma, one who had been in a horrible accident, others who had seen terrible things. This one woman was a Rwandan refugee. But what we found in that first period of working on the trauma with folks was that the core of everybody's trauma, what really the more they talked about it, what it came down to was who they had lost, who had died,

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even if they'd been through a lot. But I lost my father, but my father's gone, but I lost my friend. And so, what we did was we got these boxes from, you know, the store, the craft store, I'm going to say Michaels or Hobby Lobby. You know, we all know the craft stores, right? So, we had Michaels over here, and we got boxes, just blank boxes, and then lots of artistic materials, like lots of paints and feathers and glue and sparkles, and everybody decorated a box, picked a box, and picked a person who they had lost, and decorated a box too. Memorialize that person. So doing something concrete is very, very helpful, and we did that grief work, and then they put a message to that person inside the box, right, like I love you or I miss you. I remember one young woman, she was very close to her mom, and then her mom got dementia, and she had a disability, but she was, ended up being her mother's caregiver, and did everything for her mother. And her mother used to call her cookie rather than the name that we all were calling her by, and no one knew it. And then the message was, you know, I love you, mom so much. This is your cookie, and I'll always be your cookie. And she said to everybody, from now on, everyone has to call me cookie. And she changed her name, so we all called her cookie. You know, it just brought it up. Okay, I'm still cookie. I'm still that loved, loved young person grief counseling individually. Again, as I say, I believe it's so important, and it's not hard to do, to get therapists to do. But also, we can do grief groups without having to be trained as therapists. We can have support groups where people share about their loss, and they're very therapeutic as well, and so important. So, here's a woman that was in our grief group, and actually the healing center, and she came to us, and she was always very angry. Her name is Elena, and Elena was always scowling and angry. And when we had the drum circle, she said, I don't do the drums. I won't play the drums. I don't do this. Maybe she'd shake the tambourine a little bit, but that was about it. And we had the music therapist came and had singing, and she would just sit there, and I don't sing, I'm not singing. She wouldn't sing. And she was so angry. I thought she doesn't like us. She really can't stand being here, but she liked being in the group, and that's what I found in so many situations where folks that may not open up in every situation, once we have a group, a support group, they start to share, and they would talk a lot in the group, and one day, she said to the group, actually, let me tell you the background. The reason we have picked her for this program is that we knew that she had stepfather stab and kill a mother when she was 13 in Baltimore City, and we figured that's what we would be processing like, how horrible. But interestingly enough, what she was really suffering with, and what she opened up to the group about, was the love of her life. Who was her housemate, Mary. One day, she said to the group, I loved Mary. I loved her so much. She helped me, but then I killed her. And the whole group gasped, like, you killed her? What? And she said, I, I killed her. And then she opened up, and she told us a story that they were all they were all in the group home, and they were eating dinner, and Mary wouldn't eat. And Elena said to Mary, you have to eat. You have to eat. You have to eat. You have to eat to be healthy. And was really pushing her to eat. And so, Mary just grabbed food and stuffed it and stuffed it. And then she passed away because she choked all that time since that point, Elena had blamed herself for her death and was grieving so deeply. And this is something I've seen a lot, not just grief of the loss, but also a deep guilt, right? I was my fault, so because she shared it with the group, she got just the encouragement she needed from the other group members. They made a hug line. They all lined up, and one after another, they hugged her and told her it wasn't her fault, and squeezed her and she's just started crying and thanking them. The one woman who was a Rwandan refugee, she couldn't even speak English, but just keep saying Good, good, good, and patting her and, you know, everybody just gave her so much, so much support. And then she was able to make this memory box. That's her memory box, like I described. And here she is sharing her box that she made for Mary, the housemate that she loved. And you could see in this process of her talking about the loss, getting the support from everyone. Then we did individual therapy with her. I did EMDR with her, and then we did this project with the box that she forgave herself. Mm. And here she is. I,

**[Karen Harvey]**

and after that, she started singing every time the music therapist came, turned out she loved old Beatles songs. She would hold that mic. She loves you, yeah, yeah. She would sing Beatles song after Beatles song. Finally, we had to say, you know, probably somebody else's turn now, and you saw that smile, she forgave herself, and she began to heal. This is what people deserve. This is what we need to be doing for folks supporting this healing. Yeah, and then there's the staff. So, remember Gina? And Gina was the staff crying, right? Because she lost Linda. And staff go through so much. I think we're the only field that works with people through a lifespan, as closely as we do. If you work with kids, you know they're going to age out. If you work with older people, they're going to pass on. And that's sad, but you expect it, but it's so hard, the work we ask of staff as well, and the grief that they endure. You know, when they lose people that they support, I've had so many staff say to me, If only I called the nurse sooner, or if only I had seen these symptoms, if only, you know, sometimes people really hurt, hurt and they beat themselves up with guilt when it's not their fault. This is this person's journey, and then there's a lack of validation. So, we support each other with grief, but we don't always validate the deep pain and loss of losing someone you're working with. We really train staff to be very close to the person, we tell them, your relationship is so important, and the really good staff develop that wonderful relationship. So, it's devastating when folks die, and then we don't usually give them bereavement time. They're supposed to keep on working, just like Gina, right? She said, I just had to keep going. I had to keep things in the house going. Really tough. And so, what helps? I believe it would be wonderful if we could give bereavement time to the staff, and we could acknowledge that. And I think it's so important that we gather together and give an opportunity to honor the person together. So sometimes family doesn't invite staff or administration to memorials. Sometimes there is not a memorial. There's no money, and I think it's so important that we memorialize everybody and we have that ritual. And what's really lovely is if we can give the folks who knew that person time to share, share their memories and to have these community rituals, right, even if we may not be included in the funeral, or even if we go to the funeral and it's very formal to be able to memorialize and have our own memorial service within our agencies, and give everybody that time to share, give the staff time to share, and give the people receiving the supports time to share. And then activities I know I've seen houses make a collage and then frame it about the person they lost in the home. Do the goodbye book, do the Memory Box. There are so many ways that we can do activities together that really help process this loss. And it's, it's really helpful when we can do that, and then we have to acknowledge the importance of self-care, you know, because not all, I mean, we're talking a lot about the grief of the people we support, but it's think about that staff on the front line, that staff on the front line is supporting the person with their grief, and then they're grieving, and then they're grieving. So, we all have to stop and take care of ourselves. This is tough work, and there's secondary trauma from working with folks who are traumatized. So, we have to refill our own buckets. We have to stop and do the things for ourselves. As easy as it is for me to say, and as hard as it is for most people to actually do that and do the things that. Make you happy, whatever that is. I used to tell everybody to do yoga that how much that helps. I don't do it. I'm quite a hypocrite, because it looks like it hurts, and I don't do voluntary pain. No, thank you. But do your thing. I mean, maybe it's just vegetating, maybe it's watching Netflix, maybe whatever it is right, just we have to take care of ourselves, because we're working with traumatized people, folks who are grieving are traumatized, and we're working oftentimes with traumatized staff, and the staff are grieving, and the staff need to take care of themselves, and then we need to take care of ourselves if we're going to ever care for others. This is really an absolute. So, at that training I did on day one, when we worked with all the folks who had lost so many people, and folks shared so many stories, people who were engaged but they knew they would never get married, and then one of them died. I heard so many stories like that, while the mother didn't want them getting married or, you know, and then one dies, and they've been engaged for 30 years, so many, so many situations that people shared. And then the next day, they had me training the staff, right so the staff could help the folks with their grief. But here's what happened. I got my PowerPoint again. I was almost from out of town, at least an hour away, so almost qualified. I had the PowerPoint again, and we started talking about loss with the staff and how to support folks. Some people started crying, talking about the people they supported that they had lost. And then some people opened up about family members they had lost, right? And then we saw, oh, my goodness, the staff needs so much support as well, and everybody has to get that extra and fill their bucket, right? So, we have such a responsibility. We have people's lives in our hands. We are the one field that works with people throughout the lifespan. And Daisaku Ikeda says something, I feel so important. He said he's a great Buddhist scholar, and he said there is a great difference between simply living a long life and living a full and rewarding life. What is really important is how much texture and color we can add to our lives during our stay here on Earth, however long that stay may be. So I think that's the other take home message of helping folks and supporting people, knowing that no one lives forever, knowing that we, in this case, actually have their lives in our hands, you know, we can do so much for people to really make the texture of their life rich and bring the color to help them to have new experiences, to help them to have more opportunities, because they're not here forever, and death clarifies everything. And the very end, I asked right at that conference in North Dakota, who wants to sum it up? And Phillips grabbed that mic, and he said, live life to the fullest. And it was that was it? How can we help the people we support to have the fullest lives, the most rewarding lives, to have relationships, to have love, to have a life, a true life. I think that's what death and grief teach us to live each moment and to support each other in living the fullest, richest lives that we can.

**[Karen Harvey]**

So, along those lines, I have on my website the happiness assessment, the daily happiness worksheet, and other resources. But I want to really talk about the happiness assessment, because I have two versions, and one version is for the people we support, and we assess what makes them happy, and we help them to be able to pursue their bliss. Often, when we do this with people, we find out they love things that no one knew they loved, that they can, you know, crochet, or they liked, you know, doing basketball, but they haven't done it, whatever. And then there's the happiness assessment for staff, and I recommend that everybody do that, that we look at, how are we helping ourselves through this tough life? You know, it's short, it's not easy, and happiness is something you have to work on. So, the happiness assessment for staff, I'm the ones for the folks receiving supports. Both of them have five different categories, and those five categories are, first, is. Pleasure, which is passive. Next is engagement, which is so important. Martin Seligman says, If you spend your leisure time doing things, even if it's playing video games or cooking or gardening, versus your leisure time is passive, and you're just like watching TV, ordering out, the more active you are, the more engaged you are, the happier you are. This is true for the people we support as well. The more engaged they are in the light in their life, the richer that life is, and same for us. So, it's pleasure, engagement, positive relationships, and those relationships count and make a difference, right? And achievement. How are we celebrating people? Are we celebrating ourselves in the happiness worksheet, sorry, the happiness assessment, we talk about the achievements we're proud of. When we do it with the folks receiving supports, we celebrate them, and then, when we do it for ourselves, we celebrate ourselves, which we all should be doing. And then finally, the last category is meaning and purpose, and everybody needs that. So, we can do that for ourselves. And then the one for staff has a procedure where you can fill out a procedure for making yourself happy. What brings you joy on a daily basis, on a weekly and on a monthly to have some goals to put into place to make your life as rich and full as possible. And that's a big lesson of death, right to live life to the fullest, like Philip said. And then we have a gratitude journal, The Happiness worksheet. And the happiness worksheet is based on the work from the Emmons lab, although Martin Seligman also talked about gratitude journaling, Oprah talked about, we hear many people talk about the importance of a gratitude journal, but Emmons has a lab that studies the effects of actively appreciating right how to make your life better or how to make your life worse. Here's the study he did. He had three different groups of people, and group one, he said, okay, every day you write down what was good about that day. I saw a friend, I took a nice walk, I had a good lunch. That's group number one. Group number two, you write down the good and the bad. I saw a friend, I got a bill I didn't want to pay. I took a walk. I had a nice lunch, but I saw that there was, I heard, there was a sound in the car. Something's wrong with the car, right? And group number three had to write down just the bad. Okay, right? I got a bill I didn't want to pay, and I heard a bad noise in the car, right? So you had three groups, one just writing down the good, one writing down the good and the bad, and one just writing down the bad, and the group that was writing down just the good every single person in that group reported having more energy, being more optimistic about their life, being more hopeful, being excited about the future, being more alert and being able to focus better, all those things from just writing down what was good about that day, every day. Group number two actually reported being a little less happy than they were and a little less optimistic just from writing down both. And group number three actually became discouraged, and they reported feeling more pessimistic, feeling more tired, feeling more discouraged. And if you think about what is our natural tendency? I don't know if this fits any of you, but I know for me, my natural tendency is to think about what's wrong, what's not working, what? And I love to complain. So got to add some complaints to that. Why would that happen? I can't believe they did that. I can't believe he said that. You know, when we often get up in the morning focusing on those problems. And the reality is, if we can train our brain to focus on what's right and what's good and what's working, it makes it a lot easier to deal with what's not working. It makes us more hopeful. It gives us more energy. So, I have the daily happiness worksheet is something that folks that we support can be doing, that we can do with them at the end of the day. What was good? Three things. Was that you appreciated about this day, right? What went well, what was good? And then I added two more, because there was a researcher out of California, out of UC Berkeley, who talked about the importance of having awe and acknowledging things that are awesome. Oh, there was a butterfly that I saw, or I heard this great song, or I saw a beautiful sunset, right? And then you know what was funny is the last one. Is there something that made you smile this day? Is there a TV show that made you laugh, or is there someone that you are friends with who said something funny or did something just make you smile and acknowledging these positives on a daily basis, enrich your life, fill you up with energy, give you more hope, right and help you to move forward. And this is a part of healing from grief, right to acknowledge that we are the ones living. And I always encourage people in grief therapy like, what would that person that you lost want you to be doing right? Would they want you to be living your life and being as happy as you can be? Because the answer is always yes, unless there was a real kind of dark situation, and then, you know, you deal with that, but that's another story for another time. Yes, they would want you to be happy. Yes, yes, yes. And yes is the word we need to lead with, and yes is the word we need to support, support folks with disabilities with, yes. Let's figure out what makes you happy. Yes, let's appreciate and celebrate each day. And yes, let's celebrate ourselves, and the more we can acknowledge that we are the living, and we can enjoy life, and we can enjoy life on behalf of those who we lost, and celebrate them in the best possible way, with our own joy and our own happiness, right? And we see healing happens, and we, as we said, we're not going to, oh, one day we have acceptance, and we put a pretty little bow on it. And now I'm good, but we can step into that present and when we can help each other to live more deeply and more fully, knowing that this life doesn't last forever, and trying to get the most out of every single day and supporting the people we support to get the most out of every Day. So, at this point, I'm going to stop sharing and open it up for questions and comments. Thanks for all these emojis. They're so wonderful. Oh, thank you. Are there any questions or comments? Oh, I did see oh, I'll give that to Kristen. Thank you. You're muted.

**[Elizabeth Kries]**

Sorry! Kristen, do you want me to go ahead and start reading some? Okay. All right. Well, the first question is, what are some strategic strategies for communicating to a 30-year-old woman with a mental age of four that her mom is dying of cancer in the next six or so months, and how to help her process this information and how to help her afterwards with the grief loss, and she is partially verbal.

**[Karen Harvey]**

Oh, what a thank you so much for that question. What an important question and a beautiful question. You know, I have to say, my experience is that even though people are given age equivalency scores, like they're a four year old or they if she's 30, she's 30, and my experience with folks that I've worked with is that they understand and know a lot more than they often can express someone who has limited verbal skills and have very high, very high level of receptive skills. We don't know. My recommendation and what I've done in the past is to talk to her and explain everything to her and support her, as you would anybody whose mother was dying, and give her support in spending as much time as possible with her mother, you know, and then hopefully get some grief counseling. I know, at least in our area, hospice will give free grief counseling when they're involved. Right with somebody's death. So, if hospice is involved, you can get free grief counseling. But I think that the grief counseling afterwards is so important, and doing the goodbye book, but talking to her realistically, it's very to me. It's the worst devastation I've seen are, when people aren't told, but they know something is wrong. And then sometimes they're even not told. Family members have said, well, mom died, but we don't want them to know. We're going to wait for a while before we tell them, and all of a sudden, they're not getting phone calls. They're not they know something's wrong. So I think the best thing we can do is be very honest and talk to her in a way, with simple language, but with the assumption that she's going to understand and help her to have as much time as possible with her mom, if that, if that is a possibility, and then to get the grief counseling afterwards. Thank you. What an important question. What a great question.

**[Kristen Dahl]**

Thank you, Karen, sorry, I could not unmute there for a minute. I'm sorry about that, and I just wanted to remind everybody, remind everybody that this time from three o'clock to 315 is dedicated to the Q amp a. If you want to put questions in the Q amp a, or if you're on YouTube, someone is watching there as well. Okay. Next question, how do you effectively decipher between when someone is truly grieving and someone is using grief as a way to avoid participation far after death has happened.

**[Karen Harvey]**

Okay, thank you for that question. My assumption is that people are truly grieving, and if they don't want to do something, they don't want to do it. My experience is that grief can go on for decades, especially when folks don't have access to some way to process it, when they don't have some kind of therapy or some kind of support, or that's where I recommend the goodbye book. And helping people to process this is so important. So, we don't know that maybe his deliberately not, or her deliberately not, choosing to do something that may actually be still part of the grief. And, you know, we don't know just how deep and how far people's pain goes and how long it may take. So that processing is so important if we can help them in that way.

**[Kristen Dahl]**

Thanks. Karen, okay, next question, how do we help our community process the grief and fear of the political acts happening in our work world?

**[Karen Harvey]**

Oh, I wish I had the answer. What an important question. And you know, the one thing that I've been comforting people with I have, I have somebody, individual that I used to do therapy with, that calls me every day now in a state of panic, and other people who talk to me and people I work with. But you know, there's a wonderful phrase from ancient from long ago, this too shall pass. This too shall pass, this the we will endure and this too shall pass, you know, and I comfort people in that way, because nothing ever, nothing political, lasts forever, at least in our country.

**[Kristen Dahl]**

How? Do we help our community? Oh, sorry. Do you have any tips for helping staff process feelings of guilt?

**[Karen Harvey]**

Oh, yes. You know, I think it's so important that we immediately debrief with people as soon as they've lost someone. And you know, it's very powerful if they can debrief with their supervisor. I've been in situations where the supervisors immediate response was, well, did you do CPR, and did you do it in the right way? Did you do it? And then the person feels more guilt. I think it's so important that we say, first and foremost, how are you and that we find immediately make time and find time to sit with that staff who just lost someone and to reassure them that this was not their fault, and you know, even if they made a mistake, that this was this person's time, regardless, I think it's so important your question is great because you're acknowledging the problem of the guilt. I've seen it so frequently, and it's very powerful if right away that supervisor can be there with them, saying, are you okay? This was so tough, and giving that staff and coming from the direct supervisor or the person above the supervisor, is very powerful. I know I was asked to do a lot of debriefing with a lot of deaths in different places that I work, and that was okay, but I wasn't their boss, and often people wanted their boss to know what they'd just been through, so that that debriefing with the supervisor asking the right questions, are you okay? Do.

**[Kristen Dahl]**

Thanks. Okay. Next, would you please address a sibling loss? I my adult son's guardian. I did grief work, but he did not. He has fetal alcohol syndrome and lives in a host home. It's been almost 10 years since my daughter died suddenly from a birth defect.

**[Karen Harvey]**

Oh, I'm so sorry about your daughter. I'm so sorry. Yeah, I think, you know, thank you for this question, because you are just right. I mean, he has to help, have some help with this. That's a big, devastating loss for him. And you know, if you can recommend to that agency that they get him counseling, then that you find someone who knows how to do grief counseling. I mean, it's not a, it's not even a big area, someone that will just process with him, but the therapy can be very effective. And folks with fetal alcohol, you know, that’s, that’s, that's, that's oftentimes you see people who can, who really can process quite a bit, who can really talk things out and really do. I've worked with a number of folks with fetal alcohol syndrome who really benefited from counseling. So, thank you. And there was someone named Karen. I know she had asked again if we saw, okay, good.

**[Kristen Dahl]**

Yes, Karen, we see your question. I've got a couple more that came in before yours, and then yours is coming up is the happiness assessment based on the PERMA model of wellbeing?

**[Karen Harvey]**

Yes, thank you so much. So, it's this out of the same school of psychology, positive psychology, and the PERMA model from Thomas. He studied under Seligman. So I read Seligman material and developed the happiness assessment, and he talked about PERMA, and then Seligman talks about PERMA, so it's all positive psychology, yeah, and I believe we need to embrace this, and it's how people move forward, you know, and are able to enjoy their lives.

**[Elizabeth Kries]**

Okay? This question is, when my husband passed away, I could not find anyone who understood the IDD community to speak with my son about his dad's cancer and the grief after his passing. What do you suggest on how to I can change things in my area to get more grief counseling for the IDD community. And I believe this comes from Northern Kentucky.

**[Karen Harvey]**

Oh my gosh, I'm so sorry. I'm so sorry. I'm so sorry about your loss, and I'm so sorry you didn't have what you needed for your son to process it. I really apologize on behalf of our society that just doesn't get it and the disparity in mental health services. I had a friend, her daughter had a sexual assault, and she had to go. She went through 15 therapists before somebody would agree to work with her daughter because her daughter had autism or has it. And everyone said, well, I'm not trained, and that was just beyond ridiculous. So, what she did was she found somebody straight out of school who didn't know that she didn't know, who ended up being a wonderful therapist for her daughter, and really helped to process that. So, I think some of the newer therapists that are, and younger therapists are much more open. That's been my experience. When I do training with therapists, not to promote it, but I do have a book for therapists called Healing and Trauma, and it has materials that can be used on any level. So, they can be used some of the materials can be used by DSPs, and then there's a lot of materials to be used on a higher level for therapists. So, you can give them the book, make them buy it and not you. And then, you know, say, oh, and here's some tips, because I have a lot about grief counseling in there. I'm trying to get more things out there so that therapists will understand that this is really important and wonderful work and find the younger ones

**[Elizabeth Kries]**

and kind of going along with that answer. Karen, there's a question that says, are there videos and other resources you have identified as being effective tools to address people with IDD, with grief and dying issues?

**[Karen Harvey]**

I wish I could say that I can, that I have, that I would love to develop, that I have, there's a wonderful company, intellect ability, and where we did some work on trauma together, and E Learning course. And I'm, I'm asking them, I think we're going to be able to do a series on grief for folks with IDD. I'm trying. I bet there's things out there, but I can't tell you anything that I know of right now that just directly addresses this. I know Dave Hingsberger says a lot of things about it and open future learning addresses issues that are very related to that, so that might help.

**[Kristen Dahl]**

Thank you for these resources. Karen, it is always wonderful to learn from you. Are we able? To share them with others we work with in our Greek communities,

**[Karen Harvey]**

everyone's going to think I planted that question. Yes, please, please. I have, in my third book, I have a lot of social stories, and the social stories, some are about loss, and I have all kinds of materials. See, you're like a plant, and on my website, they're all free. On karenharvey.org you've got the goodbye book, my book about my recovery, my book to celebrate myself, workbooks that you can do with folks. And I think all these things should help, at least help somewhat.

**[Kristen Dahl]**

Thanks. That was, that was your easy one. Okay, now back to the one's the plan. We've got about three minutes left. I think we've got about three questions left. So, families often talk about their loved one with IDD being stuck in grief. How would you respond?

**[Karen Harvey]**

Well, you know what? Haven't we all been stuck in grief? I mean, those of us who have lost loved ones, this is grief. This is the nature of grief. This is the way it is. And there is no acceptance. There's just waves, right? And if someone's more sensitive and has less people in their lives, then it's more impactful. They're not stuck, they're just grieving. I believe it's very important for folks to have friends who are unpaid, and relationships and widen their circle. And that's one thing that does help, and we can encourage people. Can you help them to have a social circle so that there are others in their lives?

**[Kristen Dahl]**

Thank you. Okay, okay, how do you work with someone who is non speaking and really isn't able to understand?

**[Karen Harvey]**

That's a great question. So, one thing that I've done, I've used music and movement and dance to the song, and then I talk to people about someone who died, and we say goodbye. My experience is with folks who are non-speaking. Folks get it. They understand a lot more than we give them credit for. And I have worked with people who really got it, that that gentleman who just kept saying no book, he was talking about someone he lost, and he knew that's what we were talking about that day, and he was dismissed by a lot of people. Oh, he always wants no but he's talking about pens. Don't give him another pen. And you know, with all due respect to them, he was trying to express his pain. So, I think, assume that they are grieving, assume that they get it and talk with them. Maybe have some songs, you know, sad songs, happy songs that you can, you know, share with them, and talk about that person, share with them, and talk about the person, because they do get it in ways we can't even comprehend.

**[Kristen Dahl]**

Thanks. Karen, okay, it's 3:14 Elizabeth, is there anything left? And

**[Elizabeth Kries]**

yeah, we have a couple. The next one is, how does how to support a person during times of year like holidays that trigger deeper, deep grief?

**[Karen Harvey]**

That's such a beautiful question. Thank you. Be prepared for that, know that, and maybe you can plan some kind of memorial activity around that when you know it's mom's birthday, or you know it's Mother's Day. And I, what I've done with folks is I've gone to the grave with them on those holidays, and that's been very therapeutic. I had several people where we would go get the flowers, and then we would go visit the grave on those special days. So, acknowledging it and doing something on that day is very, very helpful. That's such a sensitive and wonderful question. Thank you.

**[Kristen Dahl]**

Okay, our time is 3:15 Karen, can we send you the other questions afterwards? Sure. Okay, so we'll send them to Karen. We'll grab them from the chat, and we can include some responses to that in our follow up email. Thank you so much for being here today. Please fill out the evaluation. Let us know what you want in the future, what you'd like to see, what needs to change, how we can be serving you best. And we will send out the slides the recording, and if you want certificates of attendance, we'll let you know how to get this so thanks for being here today. Everyone. Have a great afternoon.

**[Karen Harvey]**

Thank you, Karen, thank you. Thank you so much. Thanks to everybody. Thanks for not leaving you.