S.I.L.V.E.R. Ask Me Anything about Forging a Resilient Alliance to Promote Connectedness Among Older Adults with a Psychiatric Disability with guest experts Dr. Laura Leone, Lyn Legere, and Karen Gross

This call is being recorded.

Lisa Krystynak:

If you want to get us going. Alright. Well, hopefully some others will join us, uh, as we get, get on with the show, so to speak. But good afternoon, everybody. Welcome to ask me anything about supporting individuals to live as vibrant elders in recovery, or as we lovingly refer to it as silver, with our acronyms. Um, with our outstanding panel of experts, Dr. Laura Leone, Lynn Leger, and Karen Gross. And we are excited to have them on here today. My name is Lisa Krista and I'll be your moderator. And, uh, today kind of started out a little rough, but that's okay. That's, uh, usually that's when great things happen. We don't start out too good, right? We all have that at lived experience. Uh, and Amanda Lowe will be our wonderful tech support, which she does. Amazing, amazing work. So, thank you Amanda, for being with us today. Um, so today's event is funded by Nadler. And if you didn't know what that means, it is the National Institute on Disability Independent Living and Rehabilitation Research. Um, this webinar, as I'm going to remind you, is not a presentation, but rather an interactive question and answer period. So, you get to be a part of the show. You are, the main attraction today is asking those questions that you need in your life, in your work, in your community. You've got the folks here today that can, uh, give you some great, great, not just wisdom, but lived experience around all of it. And so, we're hoping that you can take something away today that can make things a little bit easier or better, or just get the, the education you need to start digging in deeper about this subject. Um, so, uh, the next hour our panelists will, uh, respond to questions that you, uh, have related to the topic. And our topic is forging a reliant, uh, resilient alliance to promote connectedness among older adults with a psychiatric disability. Our panelists have professional and or personal experience with this topic. So, for today, I'm going to introduce the panelist and give them a moment to, uh, expand some on our topic. Then we will take questions. Please put your questions in the chat. Uh, you can address them to the individual panelists or to the panelists, all of them. So, uh, if we're ready, let's get started and welcome. Um, so we're going to start with our first panelists. Um, going to give a brief introduction of each and give, uh, them a chance to kind of talk a minute about what we're, what our subject's about. So, our first panelist is our expert on the aging subject matter. We have Dr. Uh, Laura Leone. She is a consultant for the National Council for Mental Wellness. She has worked in the behavioral and integrated health field providing organizational leadership and direct services across the lifespan, including for older adults, having published, trained, and consulted nationally. Dr. Leoni has extensive subject matter expertise in health and wellness, including in aging and mental health challenges. So, Dr. Leoni, please take center stage and share your opening, uh, thoughts with us.

Laura Leone:

Thank you so much for that warm introduction. And hello everyone. So excited to be here with all of you connecting, right? We're talking here talking about connectedness. And this is one way that we are all connecting across the world. We have people here from the up. It's so exciting. So, thank you for being here. Um, you know, to talk about connectedness, that sense of belonging, um, to be joined with people regardless of physical location is to, I think also talk about the opposite, which is loneliness and, um, loneliness, which sometimes can be confused with social isolation. Um, you know, can be, can be two different things. So, social isolation, just to kind of level set for a minute here, um, is the near absence or absence of being physic in physical proximity to, to another person. And, um, in that absence of social interaction and social support structures, people can feel loneliness. Loneliness is something separate and different. You know, it's in, it's not, it's not the same thing. It is the possible response to isolation. Um, but loneliness is really defined as a complex and unpleasant feeling of being empty, alone, lacking that belongingness feeling, unwanted and craving human contact or that human connection. The connectedness aspect. And really it is a subjective experience. Um, and people feel loneliness, of course, sometimes when they're socially isolated, but often they could be surrounded by people and still feel a sense of loneliness. And so today talking about connectedness, um, is a part, part of that conversation is really addressing, um, ongoing, pervasive, or persistent loneliness. Um, we know that loneliness is as bad for you as actually smoking 15 cigarettes a day. It's worse for humans than obesity. There are so many health risks that are associated. And then when you think about our individuals living with mental challenges, uh, you know, and already experiencing other problems, it really can exacerbate their health conditions overall as well as shorten their lifespan. Um, we know that there's lots of, unfortunately negative consequences associated with a lack of connectedness. So, part of the conversation today, and I'll very quickly turn it over to Lynn and Karen to also introduce themselves and talk a little bit more about that connect connection. Um, you know, some of the sort of general thoughts and experiences are on how we help build resiliency. And resiliency really can be about skills that we help people hone, build, and achieve and continue. Um, and ways that we can enhance our protective factors or ways that we mitigate or lower that risk of ongoing loneliness and how we can enhance connection through, um, building those skills through things like volunteering and co-housing, self-compassion building, um, being able to think about even just how we regulate our emotional states. Um, so there's lots of different ways that we can do that and hopefully we'll get into some of those soon. I'll turn it back over to you, Lisa.

Lisa Krystynak:

Thank you, Laura. That was beautiful. Thank you. Um, so let's go to our next panelist. Um, this is Lynn Leger. She comes to share with us as a person with lived experience. So according to Lynn, she has lived a life in many chapters. And I must agree, <laugh> and those of us that know Lynn know that is so true. Her book would be 40 inches thick <laugh>, inches, inches, including living as a mental patient and building a life in recovery. Now at 70, she is in a new chapter, navigating life that in part includes consequences of the past and recovery tools to thrive. So, Ms. Lynn, if you'll take center stage and share your opening thoughts with us,

Lyn Legere:

I'd be glad to thank you and thank you Laura as well. Um, some really, uh, thoughtful, meaningful words, uh, that's what, um, the Center's work is all about and what we're hoping to be doing with a lot of, uh, y'all out in the community. So, I am very pleased to be here. Uh, as Lisa said in my bio, as a 70-year-old woman navigating this, uh, chapter of my life. And as a person who lived from 18 to 47 with the identity of a mental patient and experiencing utter devastating loneliness over those years, I see myself now luckily almost living life in reverse in that it was terrible at the beginning and now it's getting better. Every, more I go, the better it gets. Um, which is really a, a wonderful thing. But nonetheless, this needs for creating connection have still confronted me as it does all of us at different points. For me, this was a particularly acute several years ago when there was this huge disruption of my entire social network, um, due to an event. And I found myself with a close friend, but she lived about a half hour away and we're both working, so we might see each other every week, every couple of weeks. And other than that, I was living alone in a new town and working alone from home. And so there really wasn't much in my life that brought people into my daily activities. And I realized as I was experiencing on this loneliness, that I had to find a place to meet people. And so, my first go-to I think like many of us was church, okay, I'm going to go to church. And despite efforts of going week after week, after week, whatever it was, the connection just didn't come. And so, I felt like I was sort of left in the pick of like, oh God, I've got to go out of the box and figure this out. And so, knowing that it wasn't going to just fall in my lap, sadly, cause that's really what I wanted. I wanted to sit in my living room and have connection somehow just magically. Um, but it wasn't going to happen that way. So, I realized I had to sort of plan for myself that I could work through. And so, I started by thinking about, you know, the easiest part, what do I like or what am I interested in? And I have to say in a way that's hard for me cause I'm more of an introvert than an extrovert. And I don't like places where most people go to meet other people. So, I had to think like, what is this place going to look like for me? So, it had to be somewhere that I was interested in, but I also had to look at what were the barriers and how could I get over those barriers? How could I find a way to work through barriers to someplace that I might want to go? Um, and so I this idea came to mind that my top interest in life is my dogs, just as they live with me, uh, closest in my life. And so, I started going to the dog park in my town. And one of the great things about this is it avoided the biggest barrier for me, which is opening the door to a room full of strangers. That for me is like the most intimidating thing in the world, which most people are surprised at. I don't come off like somebody's scared to open that door, but I am. So, I just had to go through a gate, and I saw what I was walking through before I had to go through it. So, it eliminated my greatest barrier. So, I started going to the dog park, but at first, I sat on a bench where no one else was sitting, of course. And it took, uh, you know, a week or so until my brain said, uh, Lynn, your kind of defeating your own purpose by sitting away from the other people. Now I was loving the dogs, but I also, I needed people too. So, I started sitting near to other people and then I noticed routines saying people were coming at the same time every day. So, I sort of modified myself to that so that I could start seeing familiar faces by coming at the same time as other people were. So, I was starting to make inroads into saying hi to people because they were familiar now. And then I learned there was a Facebook page for the park. And when I went and looked at it, I saw that there were photos on that Facebook page. Well, my second love max, my dog's photography. And so, I decided I was going to start bringing my camera to the dog park. And so, I brought a blanket so I could sit down on the ground near a bench with people. cause I was working it this way, so near a bench with people. But I sat on the ground where I could get good photos of the dogs. And then they started posting them on the Facebook page. And then what happened was people started to come up and thank me for the great photos I had taken of their dogs because deep down dog owners are dogs of our kids. So, it's the same way if some days are nice, but you're your kid. So, people started to come and thank me for the dog photos, and we'd end up in groups of two or three and conversations started, and then deeper conversations, and then meaningful conversations and eventually friendships. What I didn't plan and never expected really, was that the small effort of just going in and taking those photos started a community growing in the dog park. And not just for me, but for the other people there as well. That little act of getting myself out my own door and through that door and doing the photos changed the culture of that dog park. So much so that in fact, which I think is a riot, the local TV station came, this is several years into this, and they, uh, did a story about it for the local tv. I got the CNN Hero award for doing this. And I have a plaque now on one of the, um, uh, benches that says, dedicated to Lin Layer, the mayor of the dog park. So, from lived experience, what I can say is that connection takes work to start. It's sort of like if you want to grow a plant, you got to go out and do the work of digging that hole and putting the seed into it. The upfront work had to come from me, and I had to walk through some of my fears as well as strategize. How could I set it up to involve the fewest number of barriers that I could. But also like that seed, once connection is planted, once it starts, it grows. And so that's what I want to share is the work is hard, but it pays off tenfold. And that now I have a whole community that I never expected. And that's my story and I'm sticking to it.

Lisa Krystynak:

<laugh>. Thank you, Lee. And it's a beautiful story, beautiful story, and I know so many of us can connect with so much of your story. So, keep those questions coming. We're going to get right to them once we, oh, there it is, there.

Lyn Legere:

It is. My hero award.

Lisa Krystynak:

<laugh>. She has proof <laugh>. And we'll get to those questions in just a minute. After we, um, introduce our final panelist to Ms. Karen Gross, um, I'd like to present you, I, she comes to share her experience as a family member, a caregiver. She has been an advocate and caregiver for an older sibling who experiences severe mental health challenges. So, Karen, if you'll take center stage and, uh, share your opening thoughts with us.

Karen Gross:

Well, I just want to thank Lynn and Laura and I just love Lynn's story of her connection because, uh, I think that's, uh, what I'm trying to do with, uh, my, uh, my, uh, family member, my older sibling, um, uh, to provide him, to give him, to curate a healing recovery connection because, um, basically, uh, we're, we're sort of isolated here on some property and my folks were, uh, they were, um, heroes. They were, uh, they were, uh, of, uh, trying to set him up so that he would be able to recover and not just be, uh, some kind of a, a bait, or a cog in an ugly system. They were very concerned about that for him. So, um, and uh, so they got me on board after he came here from California and they realized he had a mental illness and they had him, uh, involuntarily committed and they got him a diagnosis.

Karen Gross:

They wanted him to have healthcare, they wanted him to have help because they couldn't do it all themselves. They couldn't do it all themselves, themselves. And he had been homeless for years. And basically, his diagnosis is one that doesn't recognize as one of those that doesn't recognize they have a mental health issue. So, I am so, uh, I've known him all his life, right? So, so I know he is not violent. Uh, he can get very angry, but I've developed skills because, uh, I've, uh, to learn how to mitigate, you know, how to walk away so that his anger doesn't get worse because I'm a certified peer support specialist. So, I know how to deal with, um, his, and I think that, uh, he has some unusual things about his personality where he is. So, he is solitary. I wouldn't say he is lonely, but he, he likes to be in solitary, but he is, uh, had, is isolated socially, and it just, uh, in a, and I've been caregiving with him for probably over 15 years. Dad died in 2014. Uh, so, you know, I, I've, I've been very major then. But even before then, because dad died, he was over at a hundred, you know, so I had to take the reins there. Um, so, you know, my question is how do I make this, how do I bridge this gap with him? And part of the issue is that the system, our system is, uh, it's clinically oriented, uh, medical oriented. So, uh, it, you know, it hasn't really been, if he is not going to step up, they're not going to step up unless it's a crisis. Now, given a little bit, it is changing as of July 1st, there's going to be, uh, integrated healthcare and we just had a North Carolina Medicaid expansion. So possibly I'll be, be able to have a friendlier kindlier people come in, so, you know, so they're not going to, you know, and be a little gentler with him. And, uh, I did start to work on that earlier. Uh, but I, I had a stop. I don't do this full-time. I mean, I have a life, uh, I'm, I'm connected. I must maintain my own wellness. Um, so I will be trying to have them come in again. But at just the beginning of this though, uh, I was very aware that they're going to, uh, blast him with, uh, all kinds of options. There's going to be too much on the table. He's not going to be able to comprehend, he is not going to be able to process. So, I'm in a position where I must work with them even before I get them over here. Can you do that? Can you just offer, give him this one thing. Don't be saying a lot of stuff. You know, he'll get confused. cause at 72 he is also getting a little bit of a dementia. But at the same time, I've recognized that there is so much room there for his recovery. He does, he has done things that surprise me all the time. I am not a total expert on, and I'm going to call him Al, I am not a total expert on Al, and I think there's plenty of, of room in there for him to have a, uh, of higher quality life. But I am not very comfortable about the system and what the system may or may not do. Um, you know, cause they, because you know, the stories, the things I've heard, the reason we are my whole family was this way. I'm so protective of him. cause we know that the system can make a situation that if it doesn't work and it’s not helpful if it's not helpful. And I do not want to get in the middle of a situation like that in my caregiving role with my sibling.

Lisa Krystynak:

Wow. Thank you, Karen. That's powerful. And I know that, um, there's so many people out here right now that we know are caregivers and are putting out questions. So, I can't wait to get to those questions. But it's encouraging. I love, um, how pa passionate you are about him and, and being that advocate and just staying aware, but also doing that self-care for yourself, recognizing that there's many, many layers to your life and it's not just this one thing and how to integrate and how to take care of all the things. So, you have your best life too. And, and so I know a lot of our caregivers and family members out there will be able to relate. So, we'll get to those questions. Um, but thank you panelists for giving us a, a little send off on, on what the topic is about and some of your experiences and expertise. So, we're going to get to those questions cause that's what we're here for, right? Um, just remember to keep 'me going. Uh, you can, uh, ask a particular panelist if you want to, or it can just be to any, any of the panelists. Um, we also had put out there before, um, for before, you know, with the registration that you could, uh, pre-submit questions. And we got some of those as well. And I want to make sure that, um, that we get to those two. So, uh, but let's get started with the questions. And so, I'm just going to start at the, the first one. And, uh, Amanda, if you see that I have skipped any, please, uh, shoot me a message. cause we have quite a few questions coming, coming on board and I'm not surprised. Um, so we do have a question here. Um, and it says, have you found enough or a dearth of social support connections, resources for people who are more home bound, something like turn a frown upside down. I know different areas use, uh, will have different, uh, resources and availability, but curious about your expense, uh, experience around that. So, this could be for any of you guys.

Lyn Legere:

So, I know that every state, um, you know, has, um, or, you know, an organizational level of like, uh, the Councils of Aging and, um, triple A, which I forget what that stands for again, it's a, uh, aging resource support kind of, um, structure. And beyond that, it varies widely, not just state to state, but also community to community. If you are in a more rural community, you know, chances are you have much less access to resources. And if you are in an urban area, um, and I think what hard is knowing even how to find out what the resources are in your area. And I think that's where either your counsel of aging or your triple A center might be a starting point to find out what else is in your area that's sort of on the map. I think there are other, other activities or centers or programs that may be run that aren't even sort of on the map of the state program. So sometimes it's also word of mouth, sadly, to find out what's around. Um, I don't know if other people have more to add to that.

Laura Leone:

I, I would just piggyback from what you're saying, Lynn, that, you know, depending, depending on the area and especially more rural or frontier communities, there are more concerns around what resources exist. So, in a very short answer, I would say no, there are not enough <laugh> that exists. Oh, no. And but to your other point, Lynn, um, I think there are, um, there are great programs out there that need to be kind of utilized more frequently as well. So, and really thinking about how we do, how do we engage in alternative ways of connection. So, um, more and more we are seeing the use of technology. We're seeing the use of, um, connection through the virtual space like we are all here today. Um, thinking about just, um, how we see different kind of housing communities are being set up so that people who may be home bound still have shared spaces with other individuals and sort of co-housing. And, um, I know we have somebody here from the up co-housing is big in the United Kingdom right now. Um, so really thinking about just the ways that we push in to our home bound individuals, um, has also, you know, we're doing, we're seeing really great work across the nation and across the world. But more of it is needed for sure.

Karen Gross:

And I guess I'll just add a little bit, um, because, uh, Laura and Lynn are talking about alternative ways of connecting. I'm very involved with the community inclusion, and that's a concept out Temple University. Uh, and uh, basically it puts the onus on the community to be more accepting. You know what, Al is not going to be a rubber stamp of someone else, or he is not going to be in a silo with other silos. He is not going, he's totally unique. Okay, totally unique. Now, uh, with all the stigma out there, uh, there, he, you know, he could be in danger at any time because he looks different and people are people, uh, they, they, they have their rights violated all the time where they get thrown in jail and they, they're not criminals, but they have a mental illness, you know, and this is something we, we didn't want to happen to him, uh, you know, because of stigma. So, the this, this concept, I like this concept of community inclusion. I've done a few grants on it with the North Carolina Department of Health and Human Services and samhsa, where you get the community, you pressure and push the community to be more acceptant accepting of different people. So, you're not, you're not, uh, pathologizing everyone that is just so different from you. They're, they're, they're, they're not, they're not sick. It's just that the different colors of the rainbow and let's, let's bring them in. Let's not isolate them. Let's not, uh, you know, uh, stigmatize them.

Lisa Krystynak:

Thank you, guys. Thank you, Karen. Thank you, Laura, and Leanne. That was great. Thank you. Keep those questions coming and if you guys out there, uh, that are watching, have a particular resource, um, or an experience around anything that's being asked, just throw it in the chat. cause everybody's watching it. Um, we're not the title experts out there. You may have something that you want to share about that in the chats with someone. So, we appreciate it.

Lyn Legere:

And I just want to add one other thing on this is Karen's talking about the stigma, A lot of the prejudice and the discrimination that people may experience and the work that we're trying to do at BU is dealing with folks who are getting older who have had lifelong mental health. And so, we're really talking about ageism as well as mental health discrimination and the interplay of those. Um, there's a lot of efforts going around to have age friendly communities, right? And it's talking about the physical environment and so that make it more usable by folks who are older. But underlying that for the folks that we're really trying to support is still that ongoing biggest of all stigmas, which is the mental health stigma. And so how do we help folks who are aging to also be, um, overriding that? So, we've got those two things and how do we make life better and more accessible and more vibrant for people who may be having both of those coming on top of each other. Yeah.

Lisa Krystynak:

Thank you. Um, we do have someone, uh, Beth, um, who is experiencing, um, some housing things. Um, and she has been living with, uh, a relative for a long, long time. But her question, I think, um, is, is, I'd like to put it out there to your panelist. Um, she experiences depression and doesn't know whether she might want to be out on her own or not. So I think, you know, Lynn, um, you might be one to speak on this as well, about your own lived experience and, you know, when when you make that decision, when it was time for you to live out on your own and what you, you know, went through and what your thought process on that.

Lyn Legere:

Yeah, so number one, there's a shortage of housing. So, I brought the board, this is a challenge for everyone, but choosing about where are my skill levels and where are the available resource in my community is a big part. cause when we're choosing to live independently, it means that we're doing everything by ourselves. That means, you know, uh, a <inaudible>, I, you, you must carry the groceries, you must do all these things. So, I think the biggest thing is knowing what your capacities are and what you expect them to be. You know, I know it's a guessing game, but what you would anticipate there'd be over the next few years, um, as part of that decision making process of living totally by yourself, living with a roommate who's not family member versus living with family. I have a good friend, I tell her all the time, I'm going to get a, I'm going to buy one of those tiny homes and park it in her backyard because that gives me the independence that I thrive on. I just get overwhelmed with people. But also, the comfort of knowing that the support nearby. Um, there's many a time when I've had physical stuff, especially with my back. I've had terrible back stuff and I've had to use a skill that I think is harder than any other one, which is called asking for help. And so that's also part of the evaluation on that decision making. Can I ask for help? cause if we live by ourselves, you got to do it. And it's so hard. Um, so I, I think that answered the question. If I missed a piece, either Lisa or Amanda let me know if there was another Lisa there. But that's what I think about when I'm making that decision. What, what, what makes the most sense for who I am, where my strengths are and uh, you know, the places that I just really suck at. cause that must be on the table as I'm making that decision.

Lisa Krystynak:

Absolutely. Absolutely. Thank you, Lynn. Thank you. Um, so Lynn, this is a question directed to you. Um, says, do you think that if you had had someone with you for extra social support, do you think that you would have still done all you have done with the dog park? I

Lyn Legere:

Don't, but I don't know that I would've done well having that person drown to offer social support. You know, like, like everything. Were multi-layered and I needed that dose of humans in the flesh. cause I get the moon zoom all time. But I needed that dose of humans once a day but limited. Thank you. You know, I choose to live alone because I get overwhelmed. My radar is always going unless I'm alone. So, I, ironically, I think for some people, having that, somebody coming by with that social support would work well, um, for others, not. Um, and it depends on how long they want to hang them out, you know, because I only need a, a small dose. I don't need big doses. My sister, on the other hand, cannot stay by herself for more than 10 minutes. She meets people. So, it's sort of, it, it's also person dependent, but for me that's how that would've gone down. Like get the hell

Lisa Krystynak:

Outtalk my space. <laugh>. Yeah, absolutely. Um, thank you Lynn. Yeah. Oh, Dr. Laura, I have a question for you. Um, some people have compared loneliness to trauma. Is there anything you could share about that,

Laura Leone:

That Yeah, sure. Um, so what's interesting about what happens to our brain and our body with loneliness is that our, our body and our brain processes that as just the same way we process a traumatic event, adverse events, um, even chronic or toxic stress. We, our brain reacts the same way, um, for, you know, years and years. And I mean years, um, our ancestors like cavemen era have, were hunters and gatherers. They realized that their protection, their safety was with and among being with people. And that sort of got ingrained into our bodies and the way that we function. And so, when we are not regularly with people or connected to people, even if it's not in physical proximity, we sense our brain is sensing that as a safety concern. And in microseconds, our, our brain is constantly, and it's happening in sort of the lower part of our brain. And our brain stem, our is, is constantly assessing whether we're safe. And safety isn't just about physical safety, it's psychological or emotional safety. It's moral safety, intellectual safety. Like there's many kinds of safety. But when we are consistently lonely, and I'm not talking about fleeting loneliness, but that consistent lack of connectedness, that that consistent feeling of loneliness, whether we have people surrounding us or not, our brain is interpreting that as the same way as a trauma. And we go into a fight, flight, or freeze response mode for any of you that might remember this from like high school biology, right? You know, we are sort of programmed, innately programmed to either fight, or this might be a sense of defensiveness. And, and I might not actually be physical fighting or fleeing, which might also mean, um, kind of stopping or being numb or running away or distracting or freezing and, and kind of shutting down. And this response mode, we get stuck in this response mode when we, uh, are experiencing those, that pieces of loneliness. And so, then our brain meanwhile, and when we're stuck in our lower brain, it's not optimally using and moving on to our other levels of our brain. Our sort of, our middle of our brain is our Olympic system. It helps with memory and memory making and connecting emotionally. Our, the higher level of our brain, our cortex, our prefrontal cortex is sort of about executive functioning reasoning, um, learning processing. We can't learn or process. We can't function at our best when and we can't kind of connect in like our memories are not functioning the best way they can be. And our feelings are not being expressed in the best way if we are stuck in an area of not feeling safe. And that is what’s happening for people when, when this is occurring. And that leads to a whole host of other concerns, which is that other things are happening in our body. We are increasing cortisol levels; we're increasing adrenaline levels. Um, you know, we are, we're not functioning in the same way. Our cells are becoming inflamed and staying inflamed. And this leads to other health, health concerns emotionally and physically, um, that, that lead to some of the other problems that we see connected to, to experiences of ongoing loneliness. And so again, this, this, this phenomenon of what's happening in that fight, fight, flight and freeze response mode is what happens to us in inexperience’s of trauma or ongoing trauma. Um, and even if that trauma happened in the past, and it's also what we experience when we're, we're going through ongoing heightened levels of stress, same kind of response. Thanks for that question.

Lisa Krystynak:

Yes. That, that's good. Thank you. Thank you so much. Um, Ms. Karen, I have a question for you. Um, what have you learned from being a caregiver, uh, or a family member of a sibling with mental health challenges that would encourage those of us that are in the same situation?

Karen Gross:

Well, I think it can be very helpful if you decide to take the high ground <laugh>. And, uh, what I meant by that I was sort of able to anticipate that I would be his caregiver. And I, uh, got, I heard that I could get something called a special needs trust. I didn't want to take away his human rights and get guardianship. I, and I'm so glad we didn't do that because, uh, I've heard some pretty, uh, uh, some people have negative experiences with guardianship, and it takes away a person's rights. So, we got to do a special needs trust and that protect protected him where he, uh, just his, uh, basics, nuts, and bolts, uh, housing his, his, uh, benefits, um, you know, that protected him so that, um, from, so that those just wouldn't be ripped away from him. Um, so, uh, that it has given me a source of security, uh, of, uh, that I've done whatever I could do, which to me, from my perspective, is the best that I could do. There’s a lot more that needs to be done. Um, but taking the high road is one of them. And then, uh, and uh, and that was quite an experience. I just want to say, you know, talking to an attorney, one of the top ethical attorneys in the state, getting them to draft this up, I've never done anything like that before. Um, and then, uh, and then, um, not giving up on him and understanding that, um, the changes in his life can come very small and incremental, but he does have capabilities, uh, and, uh, you know, um, which surprised me sometime, uh, while it's very discouraging to be a part of, see how he has given up, which in my opinion he has. And I think if you met him, you would say, oh, well he has given up. But, uh, at the same time he is got some aspects of him, which are, have a lot of vitality and interest. And it's important for me as a caregiver to try to pull those out and encourage those in him, the good in him. And that always gives me hope that there will be a window of opportunity for his recovery that I can, I cannot now anticipate. I am not all knowing and I'm not going to be all judging of him. So, I think there could be a moment in time where I'm going to see some strides if I don't give up. And, uh, but I want to be careful cause those must be the strides he wants to take because it's him. But I can help him. And I'm, I'm right, I'm right there. And he trusts me a hundred percent and I value that trust. And I don't want to, uh, I don't want to be, I don't want to break it. I think it's so important.

Lisa Krystynak:

Thank you, Karen. Great answer. I do have a question, uh, that was sent beforehand. I want to make sure we get out there. Um, this, uh, question is from Shannon. And Shannon, uh, says, my dad is 95 and still lives independently and drives, um, my mother, who, uh, was much younger at 81 passed away three years ago. They had a busy, uh, social life, but my mother was the planner. Since she has passed, my father has attempted several times to go to social events or play sports as they did before. But he always has some reason that it's awful and puts more pressure on me to be his social outlet. It can be draining. He has more anxiety and depression when he isn't socializing. But I, but I cannot seem to help him find more activities that he can enjoy. How can I support him to find new activities and keep myself care at a pace of wellness? That's a biggie. Mm-Hmm. <affirmative>,

Karen Gross:

I have a suggestion. Um, you know, uh, uh, there's the senior center, it's here in, uh, my area. It's the Council on Aging. You could have volunteers come in and visit with them, them, it might be too many people, might be too much activity. It just might be too overwhelming. I mean, I think some of us in recovery find could understand that. So maybe, uh, you could have someone come to visit him and they'd be screened, and they would've gone through some training. And there's a lot of people who do that through the senior center. I, uh, come in and just visit with him once a week or once a month. And then also through the libraries, there are people that will come in and read. Maybe there's a good book he'd like to enjoy so someone could, could come in and read. So, my suggestion overall is to just tone down the socializing. It doesn't have to be like a big group. It can be a smaller group, or it can be one individual that has a little bit of training that can offer him some relief from the loneliness.

Lisa Krystynak:

I like that. I like that. Laura, did you have something you wanted to add?

Laura Leone:

Yeah, I was, it was reminding me of, of some of what Lynn shared and, and I think speaks to what you were just speaking about, Karen, which is sort of the idea of behavioral activation, which is to do things that we find, or we hope to find pleasurable. So pleasurable activities or they can be activities of mastery, things that we can do that we can get a sense of accomplishment from and leaning into your father. And I think this, this question is great because we've had, there are some other questions similar in the chat, um, around just sort of what's a, like a starting point for people. And I do think leaning into your interests, pleasures, or something that you want to achieve or accomplish, but ideally that where there are other people around or that there's possibility to connect with others, even if you don't, um, kind of forcing yourself to do those a little bit. Almost like homework, right? Um, putting yourself out there. Lynn did that with walking the dog. The dog had to get walked, you know, like she, she loves her dog being able to go to the dog park and then sitting there and maybe, you know, maybe Lynn, you didn't feel like sitting there the first time or really being with people, right? But kind of put, doing homework for yourself to do that and to be in that space, leaning into your, the love for photography. So, so with this question, you know, really thinking about what does your father love to do? What, what might he want to try to do less about the intensity of being around the other people. Focus on what's like internal to him of interest or of want. And then hopefully it's something that can connect and that there might be people around that with like-minded or other similar interests there. There's potential for building connection that way.

Lyn Legere:

And I want to add on, and this again from the current question and then some of the others that have come up as a supporter, it's always hard because we put ourselves in our own space into other people. So why isn't he, um, activating this himself? Why isn't he saying he wants to go do the, you know, all this stuff of what we project on people that we would want to do if we were, uh, in their situation. And so, as a, as a supporter, I think there's two sides of the same coin. One side is just listening, you know, and this goes to what Laura was saying, what's interesting to you? What kind of things would you like to do? And then really hear it and then stop. That's the other side of not you should, why don't you all that stuff, just accept that if they're not doing it, maybe it's because they don't want to. Maybe it's as simple as that. They're not going someplace on their own because they don't want to go. And that's the listening again, saying, is this something you're, I'm noticing you're not going. Is it something that you're not interested in? Or, um, Karen, I think of this with your brother so often, you know, um, is he lonely cause he spends a lot of time alone or is that something he prefers to do? And having that conversation, right? Um, because as supporter, knowing where those lines are between support and pressure, it, it can be wobbly lines, right? It's hard to know when I'm supporting someone, how do I know how to support them, but not be pushing my own agenda on them of what they should want, what they should be doing, what's good for them, you know? Um, and, and giving them that autonomy maybe just to say, I don't know, say, okay, well maybe we'll explore and experiment and find out. That's okay. You don't have to know. But giving the person really room to explore their wants and needs, um, rather than thinking that just because we would want and need something in that situation, that's what they want and need too, right? So, it's, it's such, it's hard enough to figure ourselves out, but then being supportive of someone else just ups the ante of challenge that goes with it. Right? So.

Karen Gross:

Oh, go ahead Pam. I expound on, on my experience of that. I think it's such a great topic and you made so many good points, both of you up. I think Laura talked about, uh, well the, the phrase was used forcing good behaviors and I put down encouraging good behaviors. Okay, because, uh, uh, because like for my sibling, al there's things he likes to do. One thing he loves to do is when I take him out to eat, and particularly I'll take him out to breakfast. Now I don't do that enough. I might do those four times a year. If I had the support from the system for him, if he would agree it, I would have, he could go out every week probably, you know, uh, with someone and have breakfast and he just like to sit there and eat. But he likes the companionship, and he likes certain restaurants, you know. So, uh, that is an activity he really enjoys and it really, it only involves a little bit of talking, but he loves eating. Now, when I said encourage good behaviors, because sometime in this case of my, my sibling al it's what is good for the community, not just for my sibling. I'll give you an example of that. When my mother was passing, uh, I, he didn't want to go see her, she passed it home and I told him, and he didn't want to come over. And so, we would just continue to go into town once a week for his town run. And uh, then I realized, because I was grieving, I realized he is not bringing his garbage over. He had stopped bringing his garbage. So, I went over to look, and here I found just about all his cabin had been thrown out in the back of, uh, the house down the ravine. I was absolutely horrified. And uh, I had to, uh, I called someone on the phone, I said, what's going on? And the person said it was a counselor, you know, and said, uh, well, you know, different people have different ways of grieving <laugh>. So, what I had to try to do, and this was very simple. First, I had to get, I wanted to get all that cleaned up. That was number one. And that became a big thing. But number two, I wanted to get him to change his behavior. I wanted to get him to bring his sacked garbage over to the car so we could take it to the dump before we went into the town. And I had to really work on him with that. I mean, little by little, uh, you got, and I wouldn't, I say, bring your garbage. We'd be ready to go, go get your garbage. You know, I really, really had to work on him to do that. And by golly I did succeed. And so, you know, because I did it with a lot of persistence, uh, but a lot of kindness and I didn't, uh, you know, but he can be very, very stubborn, uh, and determined. So, uh, that is very frustrating. Part of the caregiving that I have with him. Get this thing in his head and he is not going to change it. And there's a bunch of stuff like that. And I'd really like some help with that because some of that is the case of the garbage can become extremely dysfunctional and that's not just his dysfunction. It becomes a problem for the, let's say the community because you must deal with it.

Lisa Krystynak:

Thank you, Karen. And I.

Laura Leone:

And I just, I do want to say, yeah, when I was talking about forcing, it's maybe forcing oneself, but never, it's never about forcing another person. Yeah, for sure. You know, Karen, good call out for the, we want to encourage others and be there and supportive, but it's not about force cause force is met with defensiveness and more force.

Lisa Krystynak:

Absolutely. And just recognizing that that was some grief, that that behavior was, um, a cry, uh, sort of, of what the loss he was feeling. And uh, and I'm glad that you were able to get that information because you know, you may not ever think about that. Um, cause you, you were in your own right. So, I think that's, that was great. Great stuff there. Absolutely. Um, wow, we're getting to the close <laugh>. Um, I know we've had a lot going on in the chat and you guys have been great about putting resources out there for others that have asked for them or things that you've used. We will send those out. Um, once this is over, we'll collect all those and we'll send it out to you guys. So, if there was something that you didn't see or didn't get quite jotted down, we will do that. cause I know a lot was coming out. Um, any questions that I missed? It seemed like there was a lot going on in the chats with, um, each other and I tried to catch them all. Um, or, uh, Laura did a great job of kind of taking a few that she saw and go ahead and put, put it out there. But, um, yeah, I tried.

Lyn Legere:

To answer a few too. Yeah,

Lisa Krystynak:

Yeah, yeah. There's a lot questions. Yeah, there's a lot. Um, I guess Lynn, um, the only question that I, that came to us, um, I want to make sure I get those, uh, people that sent, um, beforehand was talking about, um, the difference. You know, and you even mentioned, um, consequences in your bio. And this, this question was pertaining to, uh, the difference in, um, someone who is just aging versus someone who has had a lifelong mental illness struggle or challenge. So, uh, can you just quickly, uh, uh, answer that question for us? Yeah.

Lyn Legere:

Absolutely. You know, I, I think the struggle with mental health and, um, aging is that first, me, our systems are integrated. Um, and that different things that are going on in our body as we age impact our mental health. And depending on, um, if a person is in recovery or, or how much exposure they've had to recovery, um, how much support from a recovering community they have now really matters as you're going into this aging process, bringing in new systems, you know, you're leaving, uh, not leaving, but you're adding on this whole system of care that's not what you're used to with new people, with new stigmas against you because you have mental illness and you're coming to them for comorbid thing. Um, and for a lot of us experiencing things younger than other people might have because of the medication that we were on for years and so forth. And so, getting that support around aging ultimately helps us age more gracefully with our mental health challenges. You know, because you got to keep doing the recovery work, but sometimes got to do it a little stronger now. cause there's other things coming up. Um, you know, so it, it just, I think it's a time of wonderful opportunities, especially we're in recovery to enjoy life that we may not have ever expected, which is wonderful. Um, and, and maybe if we're in recovery, we have more tools to deal with some of the aging issues. Um, for people who are still struggling, I think it's much more challenging. cause now you've got two systems to navigate, two, uh, funding sources to try, you know, it's just, it, it's like double duty now. And so, it's more challenging. But I'm hoping that our work and the work that other people are starting to do, that we also will have more supports, tools, resources in place so that it doesn't become double duty. cause primary duties enough. Thank you. You know, we don't need to add on, have double duty. And I think that's what we'll see, uh, over the next coming years. I think there's a real national effort to, um, try to impact, um, this group of folks like me who are now getting older, but have had lifelong challenges with mental health and, um, how do we not let that derail graceful aging or vibrant aging? So.

Lisa Krystynak:

Yeah. Well, um, Amanda, if you could put up the slide, um, we, about Laura's training that she's doing. Um, there is, there is going to be, um, another training. I can't remember what it was called. Laura, if you want to, while Amanda's going to put up that slide, and I'm sure Amanda will also send this out in the resources so you guys can have it. So, Laura, if you'll take a quick minute to, uh, tell us what this is about.

Laura Leone:

Yeah, I'd love to. So, um, for those of you who are interested, next week on March 28th at 2:00 PM Eastern, I will be providing a, um, a paid training on, um, if you're interested in that mind body connection that I was talking about, this is all about mind body responses to chronic loneliness and really getting in a little bit more deeper into sort of the, the science and the biology aspects of what we're experiencing with chronic or pervasive loneliness. Um, so if you're interested in registering for that, I have put a link in the chat. You can go ahead and click and check that out. I am, um, hoping that you'll, you'll come join me again. Thank you.

Lisa Krystynak:

Thank you. That's awesome. Um, thank you so much. Um, thank you guys. We're at the end and it is, it is time to go. But when you, um, say bye to us, you'll see a survey that'll pop up. Please take 30 seconds is all its going to take. It's real important for us to get the feedback. It's real important to our funders. And so please, please, please take a few seconds to do that. And Lynn, you're on mute. <laugh>, of course you are. Thank you.

Lyn Legere:

Said we don't, so please, please,

Lisa Krystynak:

Please. Yeah, absolutely.

Lyn Legere:

Everyone. This was lovely.

Lisa Krystynak:

Thank you.

Lyn Legere:

And nice to see some familiar names and I can't say faces, but names, uh, in the chat box. Thanks for coming and I hope y'all have a great day.

Lisa Krystynak:

Yeah, thank you guys. Thank you. Charlotte, North Carolina, <laugh>. Okay.