

Episode 14: Interview with Project ECHO in Alaska

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Speakers: Faith Kelly, Brianne Davis, Jeff Sheen, Ronnie Reynolds, Marti Romero, Alex Schiwal, Summer LeFebvre

Alex Schiwal 00:04

Music Hi, and welcome to the Mental Health Crossroads Podcast, where we explore the intersection of mental health and developmental disabilities. This week we talk to members of the Alaska Project ECHO as part of the MHDD National Training Center. ECHO stands for Extension for Community Health Care Outcomes. This ECHO is focused on mental health and intellectual disabilities. Faith Kelly is the coordinator for the Alaska Project ECHO. We talked to her and a team of clinicians in this interview. Make sure to watch our channels for future episodes, where we interview the clinicians individually. We hope you enjoy listening to this group. *Music*

Jeff Sheen 00:52

Welcome to the Mental Health Crossroads Podcast. Today I'm delighted to be speaking with the Mental Health and Developmental Disabilities Project ECHO team. We've got several folks that are joining us. We're going to go around and do just a brief introduction, so you know who's on the podcast and we'll start with Faith.

Faith Kelly 01:10

Hi y'all! This is Faith Kelly. I'm an ECHO Clinic Coordinator at the University of Alaska Anchorage UCEDD, and I am here in my basement in Anchorage, Alaska.

Jeff Sheen 01:21

Thanks, Faith. Marti?

Marti Romero 01:23

Hi, good morning. My name is Marti Romero. I am a licensed psychologist here in Anchorage, currently working from home. I am on the Hub Team for Project ECHO, and I have been serving

individuals who experienced both developmental disabilities and mental illness for about 30 years.

Jeff Sheen 01:42

Thanks, Marti. Summer?

Summer LeFebvre 01:45

Good morning from Alaska. This is Summer LeFebvre. I am a licensed clinical social worker and licensed behavior analyst here at the University of Alaska Anchorage Center for Human Development. My role on the team with this ECHO is to bring behavioral science principle to the case presentations. I am talking to you today from my greenhouse because we have sun.

Jeff Sheen 02:11

Yes, and if we had video you could see that she's clearly sitting in a greenhouse, which is quite lovely.

Summer LeFebvre 02:16

Thank you.

Jeff Sheen 02:17

Brianne?

Brianne Davis 02:19

Hello, my name is Brianne Davis. I live in Anchorage, Alaska. Professionally, I work for a tribal organization that provides social services. Personally, my educational background is in disability services, and I'm here as a parent advocate. I'm a lucky mom of four kiddos, two who experience co-diagnosis of mental health and developmental disabilities.

Jeff Sheen 02:42

We're glad to have you here. Thanks, Brianne. And then Ronnie.

Ronnie Reynolds 02:46

Good morning. This is Ronnie Reynolds, and I'm here in Anchorage, Alaska as well. I am currently a licensed professional counselor, here in Anchorage, providing outpatient therapy for families. I have over 30 years in the field working with mental health and developmental disabilities.

Jeff Sheen 03:06

Thanks, Ronnie. I have to ask, did all of you know each other very well before Project ECHO? Did you cross paths before that?

Marti Romero 03:13

Some of us. I mean, we live in a small big town. So through the years Ronnie and I certainly have worked together. Summer and Brianne and I we've crossed paths in several professional and personal arenas. And with Faith this is new. It's been great.

Jeff Sheen 03:39

Wonderful. So I had the chance to be up in Anchorage last summer, Alex and the rest of the team we were up there with Faith and had a delightful time. Beautiful part of the country for sure. So we're glad all of you are able to join us. As we get started, really, some of our listeners may have no idea what we mean by ECHO when we say Project ECHO, what that even is, and others will be a little bit more familiar. So I'm wondering Faith, if you can give us a little bit of background on the big idea behind ECHO projects in general, and go from there.

Faith Kelly 04:10

Sure, Jeff. Well, until about a year ago, I had no idea what ECHO was either. So, no worries there. In the time where we are right now, right? In pandemic time, when everything is happening over Zoom, and there's so much distance delivery of information. I think that the ECHO model is a little easier to relate to for some. So, it takes place over video conferencing. We've been using Zoom. It's a teaching model that was developed by University of New Mexico Medical School. Dr. Sanjeev Arora developed it back in 2003. He's a liver specialist, and he was trying to find a way to better serve patients who are waiting on services, life saving life altering services, where they'd be waiting for months or even years to receive these services. He had this inspiration on a Skype call with his daughter where he thought, "Well, if I can communicate with my daughter through video conferencing, why can't I communicate with physicians who I'm training through video conferencing?" And there it was born, research shortly after getting the model squared away, found that the outcomes for patients who were receiving services through ECHO trained physicians rather than university trained physicians were equal. So in those, I guess about 17 years since, it's developed into a worldwide model, where distance delivery for people who are in disadvantaged populations or rural areas, are able to receive information that would normally be siloed in, let's say, an urban area or university area where that information can get out there. In the case of our ECHO, we have an interdisciplinary hub team who you met. Each ECHO consists of a brief lecture. Following that, some questions and answers and back and forth with our participants. It's a very interactive model. It couldn't be more different from say a webinar, in that we really like to see our participants as involved as possible. Then that's followed by a case presentation, which is de identified, where a participant is able to present either a question or an issue that they're experiencing with an individual. Then the team is able to ask follow up questions for clarification, and then

recommendations follow that. So it's this model of shared learning, shared teaching, interactive between hubs and spokes. My role is really to sort of facilitate that and make it all happen. I'm not there as an expert, I do have 20 years in the disability services field here in Anchorage, but that's not what I bring to this ECHO. What I bring is the keeping things running smoothly for my awesome hub team and all of our amazing participants all over the country.

Jeff Sheen 07:18

So I want to certainly dive deep on a couple of the things that you said there. But before I do, I wanted to kind of talk a little bit about this ECHO model. So my understanding is that ECHOs are typically formed around a particular topic. So you started like with the first introduction, so as ECHOs grew they kind of were organized around topics, is that correct?

Marti Romero 07:39

Correct, correct. So they came out of this medical model, from this medical school UNM, and a lot of ECHOs are still around those medical topics. But there are ECHOs on education, law enforcement, social work, even agriculture, veterinary medicine. So there are ECHOs on many different topics, but it focuses on a topic. A curriculum is built around that topic. A team of interdisciplinary experts, who have experience in that field and varied perspectives on that topic, is pulled together. Then you identify your goal and your audience. In this case, of course, it's the MHDD community. We were so lucky to find this great hub team all locally here in Anchorage, and it's really grown organically into this national conversation that we had hoped would happen. But it sort of developed beyond our, even our initial hopes and expectations into something pretty huge and powerful.

Jeff Sheen 08:44

We're going to talk a little bit more specifically about your particular ECHO. So for our listeners, when we talk about ECHO we're talking about a model of delivery. I'm curious, so you're the hub team here for this particular ECHO. When we talk about hubs and spokes, so the hub team sounds like it's the interdisciplinary group around a particular topic. Who are the spokes? We say spokes. Who are the different spokes on these ECHO models?

Faith Kelly 09:08

Spokes are our end users. In this case, it's clinicians, psychologists, administrative folks at disability and mental health service agencies. But depending on the ECHO topic, your end user might be different. They're of all different professional backgrounds. Part of the ECHO model is really about respecting people where they're at. You may have ECHOs that are made up of folks of all different educational and professional backgrounds. So, making sure material can meet people where they are, and that questions and answers are tailored to their particular needs. So, who the audience is really would be different based on what that subject matter is.

Jeff Sheen 09:58

Okay, great. Yeah, that's helpful. So I'm wondering if anybody else on the team wanted to chime in and add anything to the kind of general description that Faith gave, or if we'd like to move into talking about this particular ECHO?

Ronnie Reynolds 10:11

I would just include family members as part of the participants as well. We have had some family members who have added to the discussions that have been very helpful.

Jeff Sheen 10:26

Thanks, Ronnie. That's one of the things I did want to ask, as we get into this specific ECHO, that you are all a part of, and that is how are you involving parents and individuals with the lived experience in your particular project? Can maybe Brianne take a lead on that and tell us a little bit more about that?

Brianne Davis 10:43

Sure. So, my role here in the ECHO is as a parent advocate, so I'm able to offer that perspective both from I think from both service sides. As a family member, receiving services, kind of talking about what we might be experiencing, some things to consider Also from the service delivery side, what to think about and what people are experiencing as they go through their journey. It's nice to be able to offer that perspective and to offer some opportunities to work together and collaborate. In every ECHO we've had, we've had some really strong family members. Some are there just as a family member role, and many are there in both professionally and personally like I am. They have shared their stories and added their thoughts, and it's really helped add this wonderful layer to our ECHO to really take our conversation to the next step. And it's really exciting to be part of that and to have this amazing platform to build advocacy and peer support. It's really a great opportunity.

Jeff Sheen 11:53

Well, I really appreciate that explanation of how parents are involved. That's certainly part of my background in the developmental disability world is, and it goes all the way back to the early disability rights movement, "nothing about us without us" and having families involved in all aspects of the care that's being provided in the service delivery system is so critical. So, I appreciate that perspective. I do want to back up a little bit. How did you even become an ECHO? How does one decide we're going to have a hub, we're going to find these people, they're going to be on our team, and we're going to start an ECHO? How does that process even work?

Faith Kelly 12:29

I'll jump in with that one, Jeff. For me, this project had already started forming before I came on board at CHD. So it was when I joined in with the project, here was this idea of we're going to do an ECHO as part of this. We have this federal funding for this MHDD project and ECHO is going to be one of the pieces there. Now go find a hub team, so using some existing connections and then building new connections, reaching out there to people. I was actually looking through some old emails recently and I was like, gosh, how did I end up connecting with Marti? And it was through Misty over at over assets, I believe, who put us in touch. It feels like it was so long ago now. But there was this thought of how can how can education and training happen on this national level? The ECHO is a perfect fit for this project, and then pulling that team together. Again, it was this exciting assignment that I got last year and now here we are with this amazing hub team and this amazing project.

Jeff Sheen 13:52

This is a good segue, because I want to kind of do a round robin. We'll start with Marti, but I would really love to hear how each of you actually came to be connected to this particular hub. Why is it that you chose to participate when you were offered that opportunity? So, why did you join? And then really, what is the benefit to you professionally and personally for being involved in a project like this? Marti, do you want to chime in on that?

Marti Romero 14:20

Sure. I'll take that. So yeah, as Faith mentioned, she got in touch with me through our chief of services. I think Faith was reaching out to all of the developmental disability organizations that she knew also provided mental health treatment and services. So not really knowing me or my background, we met and it was really serendipitous. Because about five years ago, I finished my doctorate and my dissertation was a training curriculum specifically for clinicians who had not had any experience working with people with developmental disabilities. It was kind of this no brainer moment where we had this curriculum already developed, because as they said, part of ECHO is developing the curriculum for the topic. And I already had this polished curriculum. So it really became about picking and choosing which topics were going to be relevant for our audience. It kind of went from there. It was great to be able to recommend people like Ronnie. She and I have worked together for decades here and knowing other clinical staff who would be able to add to the team. So that's how I became a member.

Marti Romero 15:49

This is what I've done my entire career, and it's the population that I'm passionate about. There's not very many of us here in Alaska. So to have an opportunity to not only connect with other people in our state who have the same passion, but to try to make an impact in this area that we all advocate so strongly for. For me it's been my life's work and this has been an avenue by which we are able to provide that information. It became something so much bigger than just our little community. We would love to be able to touch more people locally. But it has

been amazing to be able to touch people across the globe really and share information. One of the things that has really happened sort of as a side benefit, if you will, is these are all kindred spirits, if you will, who have found a group. People who are experiencing similar challenges in their work, in their role as a family member. So while yes, we do have people who I think are learning a lot and are recognizing that maybe they can serve people who have experienced developmental disabilities, because they're learning that there's research out there that shows that mental health treatment is effective. They're learning clinical strategies to try. But we're also becoming a support, I think, for people to say, gosh, I didn't realize there were other people out there who were going through the same thing, who were struggling with system wide issues in their communities. So that has been, I think, just the part that really brings me back semester after semester, is to be able to have that kind of connection with people across the United States. So that was probably more than you wanted to hear, but it's definitely something that really I'm excited about and continue to be semester after semester. And we see our numbers grow all the time. So we're creating this ripple effect and I think that's what ECHOs are all about. So yeah, it's been a great experience that I'm that I'm honored to be a part of.

Jeff Sheen 18:23

No, that's exactly what we wanted to hear from you, Marti. I actually want to hear a little bit more, because I'm curious as I listen to you, how did this become your life's work? And I'm going to ask that same question to others, so you have a little bit of forewarning. You talk very passionately about this. How did you end up in this field? How did you end up doing this work originally? You can maybe give us a little cliff notes version because I know there's probably a lot of rich detail there. But how did you get involved in this in the first place?

Marti Romero 18:51

It was kind of by accident and not. I have a family member with a disability, with a developmental disability, so I've always had that connection there. But I took a class in undergrad called mental retardation and part of the requirement was that we work in an institution. So that sparked my interest just with the population. Then as I worked as a direct support staff, and as a case manager in a variety of environments, really recognizing that there was something going on with some people that was not being addressed effectively, that people were being medicated, people were being restrained. We were using behavior management is what we called it back in the early 80s. And nothing was really working unless people were zombies with their medication. So really looking at how, these people are experiencing so many of the same, and even more, life events that we all are [experiencing] with trauma. They're experiencing post-traumatic stress and they're experiencing depression and they're experiencing anxiety, and nobody's doing anything about it. And so, really just deciding to go back to school, while I'm serving people, developing a practice to try to figure out how to help people as best as I can. Then, moving through the ranks with my role as an

administrator and having a little bit more control to say, 'Yes, we are going to serve these people because nobody else will.' Then, continuing on with my educational pursuits, so that I could expose myself to the research that did exist, to really be able to come back and say, there is evidence to say these things can work with our population. Here's what we can do as a small organization, as a small group of professionals, to serve this population. So, here I am, continuing to do direct service and also play an administrative role to try to continue to have that ongoing impact.

Jeff Sheen 20:59

I appreciate you sharing that part of your story with us. It's probably one of my favorite questions to ask folks. It's such an interesting thing. Over the last several interviews, almost all of the interviews that we've asked that question, everybody has some either family connection, or some early experience, even as early as like second or third grade and being assigned a peer mentor or something like that, that sparked their passion for this work. So I appreciate that. I'd love to hear from you, Summer, about how you became involved in this project? And how you became involved in the work that you do?

Summer LeFebvre 21:34

I work at the Center for Human Development, which is a Center for Excellence for People with Developmental Disabilities. Our mission is to increase capacity in Alaska. So when the center started to discuss this ECHO, we had a few conversations about what it might look like. I think primarily the reason I was asked is because I'm both a mental health clinician and a behavior analyst. So the majority of my licensed career has been working across systems, the developmental disability system in the state and the mental health system in the state. That being said, the reason we all know each other is because we're unicorns. Truthfully, we know each other because there aren't that many people doing this kind of work. When I say increase capacity, I literally mean get other clinicians and other people to understand a holistic, person centered approach to caring for people. This team has emboldened me even more than before to address this issue. And Alaska, the ECHO model, has really helped us get it out. We struggle with accessibility every day, because we're so spread out, and we're twice the size of Texas at high tide. So this ECHO, to me, has always been a mechanism to get this message out to this really diverse rural population that we have. I think we are working as a team to do that better.

Summer LeFebvre 23:20

In addition, I really as a behavior analyst wanted to increase an understanding of how you use behavior analysis in a mental health or complex case where you have multiple diagnoses. I've really been so excited by the group of people that come to our ECHO, because we get behavior analysts, we get psychologists, we get social workers, we get policy analysts, we get parents, we get self-advocates. We really get a diverse group, and it tells me that we aren't alone, and we may not be unicorns much longer. So much like Marti said, the system's change aspect of this

ECHO is hugely important to me. Because we've been trying to build this capacity for a long time. The fact that we have the attendance and the numbers at these ECHOs pretty routinely tells me that this is a nationwide concern that we really need to collaborate on and work together to solve.

Summer LeFebvre 24:27

My primary reason for being involved as a clinician and how I came to being where I am now is, I like a ruckus. I like challenging behavior. At the age of 15, I started working in a long-term psychiatric facility in Southern California, and I've never been interested in anything but working with folks that are struggling to get through the day. I'd say maybe in somewhat obvious ways, and so my entire life has been how do we help people have a quality of life? And how do we get people connected to the right services and the right group that's helpful? And that led me on a long, twisted path, working in mental health and developmental disabilities across systems and getting super, super frustrated with not having concrete things to teach direct support staff to help folks that were really struggling and at risk of leaving their family, or in Alaska at risk of being sent out of the state, or at risk of institutionalization or incarceration. So, I pursued a furthering after my clinical degree in social work, I pursued a degree in behavior analysis. That led me to working here in Alaska for the Center for Human Development. They had a small nonprofit that worked with folks that had challenging behavior around previously having sexually offended and they had developmental disabilities, mental illness, brain injuries, early dementia, many, many, many, many challenges. From there, I started my practice really officially across all of those arenas. So that's kind of why I'm here. I'm sorry, that's kind of rambling, but it certainly wasn't a straight path.

Jeff Sheen 26:27

No, I appreciate so much of what you said. It's certainly, as I kind of can see the participant list and who's on my screen and I'm talking to all of you, it's certainly not lost on me that I'm amongst a herd of unicorns which is very, very rare. To find one is extraordinarily rare and to have five of you here at the same time is amazing. And even better than that, unicorns that like a ruckus. That's the real gem. So I really appreciate what you were saying there, Summer. I have to tell you all that certainly, Alex and I are already thinking that we would love to do individual interviews with each of you for more about your clinical practice. We have done a lot of interviews so far with different professionals, but we haven't had a chance to really sit down with some clinicians and really talk about the nitty gritty on the clinical practice side. So if this goes well, for all of you in the future, we would love to maybe do some one-on-one conversations more about your lived experience as a clinician. That would be lovely. So thank you for that. I'd love to kind of now switch over to Ronnie. Ronnie, just share a little bit about how you became involved and kind of a little bit of your story?

Ronnie Reynolds 27:40

I always like to say I kind of grew up in the field, learning as I go, and did a lot of on the job training, learning from the individuals that I work with. So again, I think because of that work, knowing people that I think Marti provided my name to Faith, and I think we actually talked while I was actually out of state. But again, the opportunity to even be a part of such an amazing adventure has just been extremely encouraging for me. I think when Faith asked, it was like, no doubt, yes. What do you need me to do? What do I- where do I sign? It was very exciting just to be thought about. I know Marti and I have worked together a long time and being a part of various agencies here in Anchorage. It's always been a challenge to serve this population, because again, as Summer has said, just a handful of us. So I've always had the privilege of working in an organization where they have served this population. And again, I think the idea that, as I learned, it was always a privilege to share what I've learned. I think we've always had the desire to do more and carry more folks along with us on this journey. I think the key to that is being open minded and willing to learn, which is why I think this ECHO project has been so helpful for me, because after 30 years in the field, I can't tell you how many notes I write still as I'm learning as we're sharing in the Project ECHO.

Ronnie Reynolds 29:26

So again, I like to say I kind of stumbled across this field by accident, never in my wildest dreams thought this is what I'd be doing. But once I got into it, in undergrad, not having any idea what I was getting into or really how to do it. I think that was a kind of a carrot for me to step up to the challenge and figure out how to do better. During the course of my journey, I started out doing direct service work as a DSP, and again, I literally have no idea exactly how to do it. But during that process, realizing that there was more to what I was being told I needed to do, people were presenting with more of a need than what I had expected. So again, as I continued to learn, realizing I still needed to learn more and that there was more to the individual, and that I needed to learn how to work with a whole person, and not just one area or one ability. So again, it sparked my interest in continuing the field and as I met other people who had that same interest, it made it a lot easier to do that. Again, I too, have kind of taken a lot of different paths but have gone from direct service to kind of administrative responsibilities to clinical supervisory roles. Then now where I am providing direct service again.

Ronnie Reynolds 30:58

One of the things that I wanted to talk about is that in that supervisory role one thing for us to know, as the clinical staff, is to be able to pass on those strategies and our training to the direct service staff. Because they're the boots on the ground. They're the ones who are out there doing the work. For me, it's been helpful to be able to relate to those direct service staff by having that direct experience myself. When I hear that there's a whole lot of folks across the country who are experiencing the same uncomfortableness that I did, trying to figure out how to best serve individuals and families... And though there's been lots of progress made, I think that Project ECHO is an amazing opportunity to continue to learn and share with each other

and from each other. And I am so privileged to be a part of this project and it feels like home. There's been, for me, a really good connection with this team. When I was asked, it was a no brainer, of course. And I think when the first one was over, I was like, 'You got to be kidding me. We have got to keep doing this.' And when Faith made the comment that we may do a second one, I don't think I gave her a chance to say, "would you like to be a part of it?" It was like, sign me up. Because it gets better and better each time and to see the numbers increase it lets me know that this is what was meant to be. I am grateful for the experience. Even after all this time, I'm still learning and there's so much more that can be done to serve this population.

Jeff Sheen 32:51

Thank you, Ronnie. One of the things I love about being able to host this podcast... We kind of joked that we have more episodes than listeners at this point in time, but as it grows I'm excited for more people to hear from all of these people that are so passionate. The cool thing for me, as the host, is that I feel less alone. I get to connect with people that are equally passionate, and even more passionate, about this population than I have been. This is a career I came into based on an experience with a younger sibling, so I've been doing this for a while. But to find that group of people that are equally passionate about this population and improving the lives of individuals and their families, it's a really exciting part of this job. I don't want to skip Brianne. I'm going to come back to Brianne, but all of you have kind of mentioned the number of people this is reaching. I'm curious, Faith, what is the attendance? How many people are you reaching? It sounds like they're national. Can you tell us a little about the numbers that you're reaching through this project?

Faith Kelly 33:54

Sure, yeah. Our numbers have been kind of amazing right from the start. Just for a little background, a typical ECHO usually has around like 25 to 30 participants to have an effective back and forth conversation. It works really well that way. When we launched the pilot in fall 2019, within just a couple of days, I contacted the hub team and I was like, "Oh my gosh, you guys, we have hundreds and hundreds of people registering." We ended up with 500 registrations for that pilot. That was sort of our first clue that we're tapping into something pretty powerful here. We already knew we were, but we didn't even do a whole lot of outreach. It was like a couple of emails went out onto listservs and it just sort of caught fire. We were amazed. For that pilot we let about 100 people through the door for our registration, and we had an average attendance of around 40 or 45 people per session in that first series. But we had a couple of really big sessions and for the next iteration. I have to say, Ronnie, you were like the biggest cheerleader for making that happen. It was such a cool conversation, and I can remember it so well when you were like, "We got to do it again! Like, let's do it!" Like let's just jump right in and do it no question.

Faith Kelly 35:23

But for that next iteration, the winter spring series that started in January and just wrapped up in April, we decided to open up the door a little bit more. We had some folks who had participated in the previous ECHO and a bunch of new folks as well. Our average numbers were probably more like around 50 or something, and then of course, the pandemic hit. We knew that we needed to address this with our participants, and this was a direct way that we could connect everyone in this conversation. So we opened it right up, sent out an invitation to that initial list of 500. Our numbers for the second half of that series were more like around 75 people per session. At that point, the hub team had just got it down. You're all so well able to manage a conversation among the large group that our launch for our summer series that just started last week, we had 108 separate logins for that one. It was smooth and just a wonderful back and forth conversation. This team is so good at engaging with people, encouraging them to speak up whether it's via the chat box or verbally piping in. While I had my ECHO hat on, I was nervous about growing and making the group bigger and opening it up more. With the encouragement of this team, we've got to get this message out, we've got to reach all these people. It's really just proven that it is just as effective and our evaluations state that even though it's gotten bigger, our participants are still satisfied and giving us great feedback in our eval. So I feel like it could even get a little bit bigger, and we'd be okay.

Jeff Sheen 37:23

Well, yeah, those are really amazing numbers when you think about typical ECHOs being closer to 25, 30 folks. That clearly demonstrates how hungry the field is for good information. Ronnie, you talked about being in the field and not knowing what to do and not really having- So there's so many people that are in that same boat, still these years later. Thankfully, we have things like ECHO now and people that are feeling isolated, in different parts of the country, can tap into this. To realize there's a group of over 500 people that immediately want to talk about these things, that is huge and that is very exciting. I do want to go to Brianne and just hear from Brianne. How you got involved and kind of what the benefits you've seen for your participation? And a little bit of your story if you want.

Brianne Davis 38:13

Sure, my connection's a little bit different. So, I joined the Mental Health and Developmental Disability National Training Center advisory board in late 2018 and have been participating there on their board helping to create this training center so people could be connected. It was through that opportunity that I was offered that I connected with ECHO. But my journey into the field started a lot earlier than that. As I said before, I have four kiddos, two who experience co diagnosis, and my youngest kiddo in particular had some significant challenges, very significant in fact. So, we were really faced with talking about those things that everyone else is saying like out-of-state placement, institutionalization. I just thought and we reached out for help to every single organization there was in our community, and no one knew what to do. So I figured, okay, well, if no one knows what to do, maybe I'll try and figure it out.

Brianne Davis 39:19

So I started going to night school to the Center for Human Development. I was taking night classes, I did my practicum on my own, you know, with my own son, and these projects, and I enjoyed it very much. We were able to make a really big impact. So once I got my children's behavioral health certificate, I decided to keep going. It was so helpful. So, I ended up getting my degree in disability services. When it came time- when I was able, when things were more stable, and we were really able to utilize a lot of community resources and make some pretty big changes, I was able to go back to work. I didn't think I should work in the same field that I was living my journey and every day it just seemed like too much.

Brianne Davis 39:59

So, I went into social services but on the side I still like to, I mean, this is my passion. This is what I live every day, and so I always look for places where I can be involved. I served on the board of directors for the Stone Soup Group for many years, which is a local family organization here in Alaska. When I finished my time there, I was looking for some opportunities that would be a good fit. So when the MHDD opportunity for their advisory board came up, I thought this will be cool. I'll get to work with people across the nation and develop this tool that people can use. Because I know the challenges we face every day, and I'm very interested in helping create those paths for other families because I know how hopeless it can feel. I know what challenges someone might face when someone says "Hey, do this. Go to this ABA therapy." Okay, well, how do I get there? And what do I do with my other children while I'm there and how do I work and manage those appointments? There are a lot of challenges, from the family members' side, that people experience that may not be as easy to see. So bringing a voice to that is very powerful for me. You know, kind of dealing through what we've been through, and it's our silver lining to be able to connect to other families in that way- and with clinicians and professionals to help them see what we're dealing with and what we might be experiencing, to add something to the services that they provide.

Brianne Davis 41:27

So when Faith emailed me, I don't think she realized I was in Alaska when she emailed me, she was like, "Hey, we got your name that you are someone who is involved and might enjoy this opportunity to share." And I was like, 'Hey, I'm in Alaska, too.' So we met up and she explained, I'd never heard of an ECHO before, and she explained to me the model. I'm so excited to be able to share our journey and use it as a tool for others to be able to grow. I know everyone else has already said this, but I'll echo it, pun intended. Every time we do an ECHO, I just I walk away with more. I really grow and it leaves me so inspired. The people that we connect with through our ECHOs, family members, parents, self-advocates, clinicians, directors, the conversation is so rich. I feel like we're all more for having shared those moments together.

Jeff Sheen 42:21

That parent perspective, Brianne, being involved and the expertise of the lived experience, right? Whether it's a parent or an individual that experiences both ID and MH, mental health and intellectual disability, it's the expertise that comes from living this journey that is so valuable. Then, as clinicians and other professionals, the expertise that comes in from seeing a wide array of families that are going through this journey, being able to see patterns and see themes and figure out ways to help as many people as possible. So this idea of this interdisciplinary team is just such a beautiful thing. I would love to talk a little bit about some of the mechanics. Right, so you talk about kind of how an ECHO session goes and what are the pieces of that. I want to talk a little bit about when you staff cases, so that seems very meaningful to the person. That's the case that they're bringing to the team to staff. What are some of the benefits of that? But what are some of the challenges that might come up in staffing cases with a group of 75 people or however you go about doing that? So can you give me just a little bit of a quick overview of the actual process of staffing a case in an ECHO meeting?

Faith Kelly 43:36

I'll jump in, but I just have to say that Ronnie, I think we all bow down to Ronnie on this one, because Ronnie has taken on the often Herculean task of managing that delicate territory of supporting someone through presenting their case. Sort of the first step is encouraging people to go out on a limb and present that case, which puts you in a vulnerable position of asking the question. "I don't know what to do, please help me," that's a vulnerable spot for anyone. For the majority of our ECHOs, getting cases submitted and seeking them is probably the hardest role for any ECHO coordinator. In this ECHO, in particular, however, because we have struck this sort of magic chord with people, our cases just sort of come pouring in. We've had loads of people interested in having those cases. So there's some preparation that happens on the outside end, but then we hand it over to Ronnie. Then Ronnie, if you want to talk about what that looks like in action? It's all you, so thank you.

Ronnie Reynolds 44:53

Yes, again, I am honored to be in that role at this time. It has been very interesting. I can tell you I was a little nervous at the beginning, thinking how do you facilitate a conversation with that many people? But I think it's been amazing honestly. Again, our presenters have been really good with sharing the case. It's nice to be able to solicit feedback in questions from our participants, as well as to ensure that our presenters are providing enough detailed information without breaching any confidentiality of the case they're presenting. So that's been really good. And the larger the number of course, and depending on who the participants are, you want to encourage certain participants sometimes without calling a particular person out directly. So trying to pay attention to who is actually participating, and encourage those participants to

share, whether it's from a clinical perspective, administrative perspective or a policymaker. So just depending on the case that's presented and the question that is asked of the presenter, I think that's where I usually try to get my guidance from and how to solicit feedback. I think it is important, part of that is to encourage the participants to participate in the discussion and share their experiences. Because again, the idea of this project is that we all are learners.

Ronnie Reynolds 46:51

If we don't hear from our participants, then we're missing out on a valuable piece of this project. I think the team really helps in paying attention to the chat box. Because you're looking at the chat box, people are responding and asking questions and sharing recommendations that way, as well as verbalizing their recommendations and suggestions to the presenter. So, it really is a group effort. Depending on what the case is, and what the discussion is about, including our hub team to share their expertise. That's another opportunity to encourage them to chime in and trying to put them in at the right spot. We're kind of talking sidebar amongst ourselves to make sure that we are sharing our experiences and what we know on our end as well. It definitely takes some skill. Again, I'm fortunate that I was asked. I probably wouldn't have ever necessarily volunteered, but it's been great and I enjoy it.

Jeff Sheen 48:13

Let me ask this, so if I'm a clinician and I bring the case to this group, that's going to be incredibly beneficial to me to get all of this kind of wisdom and input and guidance and questions. That's going to be very, very clarifying stuff. I'm a clinician in Logan, Utah and this is the first individual I've served that has this co-occurring situation. This is going to be incredibly valuable. For other people that might not be staffing the case that day that are kind of listening in, maybe it's a direct service worker, what are the benefits? What are they taking away? What do you think they're taking away from this? Is it listening and being able to generalize to their situations and pick up little tips and things like that? Is that the benefit? What are your thoughts on that?

Ronnie Reynolds 48:55

I think again, part of the lecture is providing some kind of overarching information for folks, and then again we are asking the participants for any clarifying questions. So that they can get a particular understanding of what is being presented. Also, soliciting specific recommendations, suggestions, so people are able to leave with their questions answered. They're able to kind of apply this to their day-to-day lives and the work that they're doing, and offering suggestions, as well as asking questions that would be helpful for them. The other part that Faith has done an amazing job of is collecting and compiling all of the suggestions, recommendations and making that available to all of the participants. So people can have that information later to refer back to, or people have been connected with each other. People have shared their direct experiences and any similar experiences they may have, and strategies that work for them. So

you walk away from a session with some specific information not only for yourself. At least for me, I think individually in my work as well as if I have specific cases or someone that I'm working with. I can walk away with a specific skill, or strategy, or even a resource, or know that I can go back and look in the box and there's resources and information there for me. So it's a rich opportunity of resources for people to have at their disposal.

Jeff Sheen 48:57

Thank you so much, Ronnie. I know that coming away from something with tangible, applicable, concrete ideas and resources is so valuable. Everybody's time is very important and I can see how walking away after a session like that would be immensely helpful to everybody that was involved. How does ECHO involve systems change? I think, Ronnie, you mentioned how policymakers are involved. Marti?

Marti Romero 51:20

I would just say that... Ronnie mentioned the lecture piece which is frequently my piece. I really try, while it's driven from a clinician's standpoint, to include all of the spokes and their roles and talk to how they can apply this information in their role as an administrator, in their role as a nurse, in their role as a direct service provider, or a family member. That's one of the beauties of having Brianne, because I bring the research and I bring the nitty gritty clinical stuff. Then, Brianne always follows it up with how we can apply it as a family. I think all of the things that we talk about, when Summer talks about ADA, and from coming from a trauma informed perspective, how do we take that information and apply that in our role as policymakers? We really try to take the information and help people turn the prism so that they can view that information in light of their role. I think this team does an exceptional job.

Marti Romero 52:37

We've had cases even where the issue is done and over with, but we're encouraging people to hear the information being presented, and to ask questions and provide information that is going to help people make changes at that policy level. Examples of that being, how do we get education in the university systems in our graduate programs so that clinicians are not leaving without having some understanding of this population. So, I think we are starting to have that kind of an impact. I'd like to definitely see that continue and to have more policymakers definitely at the table. But I do think that we're taking baby steps for sure.

Jeff Sheen 53:32

Thanks, Marti. Summer, did you want to chime in on that?

Summer LeFebvre 53:34

Sure. The original ECHO model was designed to get people to treat Hep C, to get doctors to treat Hep C. So, to increase the clinical skill level so that more people could get treatment. So there's that aspect to the ECHO, but the other aspect to the ECHO is this way of increasing capacity that reaches more people faster. And it has applicability nationally, right? And so the systems change piece for us, and I'm speaking totally out of turn, for the Center for Human Development, is that raising of capacity for persons that experience developmental disabilities and their quality of life. The only way we're going to be able to do it is if we continue to build these collaborative groups that are having these discussions that are including all of the stakeholders. So when I agreed to participate in this, clinically, it's not as specific as some of the behavior analytic interventions that I'm involved in but systemically it's super important. Because this discussion, as far as I know, where real people that really have people in their lives that need help, hasn't really occurred on a national level. That is super exciting. Then, being able to meet other clinicians and grow my practice and their practice collaboratively, I think is very much the way we're going to move in the future. We started this ECHO, this is an indicator for me, we started this ECHO before the COVID-19 pandemic, and we had those kind of numbers. So it bodes well for our future team, as far as I'm concerned.

Jeff Sheen 55:35

Yeah, thank you so much for that perspective and grounding it back even to the original ECHO. I've been a fan of ECHOs, and I've kind of been on the periphery of them. And I'm walking away from this conversation, just so excited about the potential for this project to just continue to grow and benefit other people. So I am so deeply grateful for your time and talking about these things and getting it out. So that is the question. If somebody is hearing this and wants to get involved, Faith, what's their way into the next round of what you're going to be doing?

Faith Kelly 56:12

We are still accepting registrations for our summer series. You would go to mhddcenter.org and there's a banner there that directs you straight to our registration page. It's an easy one-time registration and then you'll get email updates from us that invite you to each session. It's every other week on Thursdays from 10 to 11:30 Alaska time. We have the time stamps for all the other time zones around the country posted on our registration site. This is our third iteration of the series, and we're going to keep on trucking. We will have another series that will start again in the fall and then we'll have another. It's going to keep on rolling so long as we have our funding in place and so long as this team is excited about it. We're going to keep on rolling, and we're always dreaming and scheming in the background in our debrief at the end of each session.

Faith Kelly 57:21

Just quickly for a moment, while I have my mic open, I just have to give Brienne some props. As far as ECHO goes worldwide this- Marti alluded a little bit to it... Part of the ECHO model is, we

have this lecture that then leads into some Q&A, and then we have a case presentation, clarifying questions, recommendations... We added something new to the MHDD ECHO, in that we have this moment for family reflection. It came about really organically, like so many things do with this team. There's been so much with this team that has been serendipity, organic growth. I mean, it's part of what makes it such a joy to work with this group. I wish I could remember, and maybe somebody else does, exactly how it came about- but we came up with this idea that Brianne would give a family reflection, following that first lecture. We loved it so much that we've built it in.

Faith Kelly 58:25

Not only has it become a solid piece of our model, but as I mentioned earlier, ECHO is this worldwide model. It's used all over the place. There are over 90,000 learners around the world who have participated in ECHOs. There's a network that connects ECHO coordinators and ECHO staff around the world. So I've been connected with ECHO Ontario. They have an ECHO there that's around developmental disability and mental health, and they're using the same model. They said, "what tips and ideas do you have for us?" I said, "Oh, well, this thing that we're doing with Brianne is our parent reflection, is so cool." They love it. They started it with their first ECHO in that series, and they're rolling with it. There's an ECHO in Australia that's palliative care for children. They have a parent involved with their ECHO. They're doing the exact same thing, and it's been a huge enhancement to their ECHO. So we're just in the very beginning stages of it, but ECHO Ontario has reached out to us. They want to dig in a little bit more and put together some information about how this change to the model has really sort of shifted the way that a family can benefit from this, that it's not just about the professional perspective. That it's really about that family perspective as well. And I think that, Brianne, your involvement has also opened the door to make it easier for those family members who are participating in our ECHOs to feel more comfortable being part of that conversation. It just makes it all the richer of an experience for everyone. It's this small thing, but it's so impactful. This small thing that happened in Anchorage, Alaska, and got broadcast all over the country through this ECHO, is now happening around the world with these other ECHOs. I'm sure it will just continue to ripple effect from there, so it's pretty amazing. *Music*

Alex Schiwal 60:44

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