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SPEAKER:

Welcome. You are in the right place. You have come to the fourth instalment of our fringe webinar series. This is webinar number four. Family Members As Trainees and Participant in program planning, implementation and evaluation. We will wait one or two more minutes for folks to check in to the Zoom room. If you would like to download the slides today to follow you can do so at the link that was shared in the chat box.

Hello, everyone. Thank you for being here. My name is Emma.

My pronouns are she/her/they. I am a white woman with glasses and dark brown hair up in a ponytail. I am a program specialist here on the AUCD specialist team. We would like to thank you for joining us today. Part four of our Fabric not Fringe Webinar Series.

Will provide a brief introduction of family not fringe paper which is what the series is based on. Finally the presentations there will be time for questions. There will be about five minutes for questions and answers. You can submit them in the chat box, or come off mute and ask your questions verbally if you would like to.

Because of the number of participants your audio will be muted throughout the call. We can answer your questions anytime via the chat box and we will address those as they come in. Closed captioning is available for this webinar by selecting close captioning button at the bottom right-hand corner of the zoom screen. Let us know if you need help accessing that feature today.

This entire webinar is being recorded and will be available about one week from now. There will also be a short evaluation survey at the close of the webinar and we invite you to provide feedback on the webinar itself and provide suggestions for future topics.

It appears I am having a little bit of internet leg so I hope you all can see the slides OK. What you should be seeing is the agenda slide. Can I get some confirmation you can see that? Awesome. I see head nods. We will start with the introduction to the white paper webinar with Fran Goldfarb. She will be handling the rest of the webinar from here on out and it will be the family members as trainees, Q&A session, and then family members as participants in program planning, implementation and evaluation.

Before we jump in let's go ahead and respond to a quick poll to see what kind of disciplines are on the call today. We want to see what diverse perspectives are on the call today. Maybe you are here from a different program. If you are here representing a different program or institution we would love to hear

about that in the chat box. Feel free to introduce yourself.

Seeing a lot of different perspectives. Seeing some UCEDD's seeing the little bit of others. I'm going to go ahead and close the poll so we can get moving.

Please join me in welcoming the following expert in family support whose face would probabl-- familiar to you. The director of community education at the USC UCEDD at Children's Hospital in Los Angeles. Round of applause for Fran.

FRAN D GOLDFARB:

Thank you, Emma. I just want to say good afternoon to everyone and also let you know that I am here as the chair of the LEND family discipline at work. The group that was responsible for the white paper.

I'm just going to provide a short introduction and overview this webinar. For some of you this is the first webinar that you are attending. But if you have been to any or all of the previous three white paper webinars you can protect this is the sound of music sing-along or the Rocky horror picture show. And you can do the introduction along with me.

This webinar series is based on fabric not fringe white paper picture here. That was developed by the LEND family discipline network. It can be accessed on the website.

It looks at all the ways families have been involved. Family involvement sits at the core of all LEND values and core programs and it is an essential component of family centred care. Family centred care of course has evolved into family as a discipline and as you will see in this series, or as you have seen in this series there are many types of family involvement. They are all part of the fabric of LEND and not just part of French. Next slide, please.3-- part of fringe.

In 2012 an important question was posed. She said, I wonder what impact family involvement has had on all of the LEND trainees and thus the family involvement survey was born. We started the survey in 2012 and it still continues to this day.

We ask all graduating fellows about their perceptions of the important impact of having family involvement of any type in their program. To this end we identify eight types of involvement.

The white paper is really based on survey and those eight types of involvement.

The white paper contains a series of, we called them one pagers, but they are actually 3 to 4 pages. Each one talks about the definition of involvement. Discusses what types of programs that it is best for, has a discussion of need as well as effect. Resources for implementation as well as strategies for

implementation. Looks at barriers that help us to address them and then looks at how you evaluate your success in that area.

The eight types of family involvement that we identify where family members as faculty or staff. Family members as supports in clinical settings. Families as mentors. As presenters and/or panelists. Family members from the community serving on advisory boards as research participants or consultants on thesis preparation. Family focused topics. And the two we are going to be discussing today, the family as trainees, as well as family members participating in program planning and implementation and evaluation.

Many of you are familiar with LEND programs but for those who are not the LEND program is an MCHB funded program under the Autism Cares Act. It is an advanced level does interdisciplinary training program. Family participation is required but we tend to think as family participation really family faculty. We started having family faculty back in 1992. Family trainees, we hosted -- started having those in 1995, or as mentors.

Indeed there are other possible roles.

In fact the purpose of the white paper was to kind of take some of the learning that we had in our land program -- LEND program and how other types of programs incorporate family. We really feel that the act of participation and family is not uniquely suited to LEND, it has a fundamental role in the training.

So, our purpose is as a means to encourage and strengthen family involvement in any training program and to always remember that when we are talking about families we should be talking with families.

Today it is me. In previous webinars I had the opportunity to pass it on to our other family faculty, but I am going to be taking both topics today.

As you know this is session 4, sessions one and two have been archived and are available for listening. We are working on getting session 3 which occurred yesterday archived as well and that will be available as well.

Let's move on to families as trainees. In 1995 the California mileage program started up program with two-family trainees. This was actually two years before we had a family faculty, me, on board. In 2007 when family faculty had started coming together and we had one of our first network presentations we did a little survey and at the 28 that responded only 18 had family trainees as part of their program. Of those 18 have had only had family trainees for about one or two years.

That's really changed. Now virtually all of the LEND programs have family faculty and they also have family trainees. So, who are the family trainees? First of all there is not a universal definition of who can be a family training, and in fact we don't even call them by the same name or the same discipline but they do share three common features.

They are the relative of a person with a disability. They have lived experience. And also they have leadership or advocacy experience.

Although their roles may vary we also identified three common roles and those work providing the family perspective, representing family support or family as a discipline, and also to serve as navigators to the system serving people with disabilities.

So, having family trainees what types of programs are they best suited to? Well, first of all programs that are interdisciplinary. Family in many LEND are considered professional discipline and their goal is to support leadership and discipline specific tales -- specific skills for the family. We see that transfer to other types of training programs.

That they are best suited for programs that do not require university enrolment. When we think about LEND we tend to separate them into two categories. University or hospital-based. University-based programs may require all of their trainees be enrolled in the University. For some this can become a barrier and we will talk more about that.

That they value learning with and from families. It is always important to see that we look at the width and from being vital components. That they have existing family faculty to guide mentor trainees. And really the value of family faculty, regardless of the type of training program, it should not be underestimated.

The faculty understand the role of the family member, they understand the discipline of family, and they have a connection to the disability community. They are also in a position to support and mentor their family trainees. And certainly this is best for programs that are open to differentiating their curriculum or developing accommodations, or modifications, to support diverse learners.

So, in talking about need I am going to separate this into two categories. First, the need that is addressed for train family members. We know more and more that we are seeing programs and systems that require the participation of family members. This is in leadership positions, and working with direct support services, as part of interdisciplinary clinical teams, and policy and systems change, and also family as systems change leadership.

The need for family members to have access to the same leadership training that is available to other

professionals in the disability field.

What about the needs of trainees from other disciplines? Other disciplines need to learn from and with family members to fill the commitment to family centred care and parent professional partnerships. It is really difficult to have a commitment to those without involving families in that process.

We also know from the (Land Acknowledgement) family involvement survey -- LEND family involvement survey is important and impactful. We have been including family training is for more than 20 years and family now is one of the core disciplines required by the maternal child health bureau.

So, what are some of the benefits of having family involvement? Again, information gleaned from the survey really looked at the importance of having family participation. 90% of fellows rated the inclusion of family trainees as important, or very important and rated the impact as high or very high.

Some of the examples of reported benefit include the helpfulness of hearing about family members views and opinions. Increased awareness of the family perspective. Broadening their perspective to view family as peers, increased appreciation of the value of parent to peer support.

We also saw there were direct benefits to family trainees. Those included an increased appreciation and strengthening the potential for true partnership.

That understanding perspective goes both ways and it is equally important going both ways. We also know that family members who attend LEND are sometimes a little older and more experienced with service systems and they are able to provide a more realistic understanding of how those systems work.

So, for programs that are just getting started with family members as trainees we have some strategies for implementation. The first one is it is a helpful to start with a family faculty member. That smooth way for family trainees to come in and helps them feel like they have a specific discipline at specific discipline support.

It is also important to remember that family members may have very full plates. They are not only taking care of their child, of any age, with the disability but many of them working full-time, or very committed to their activities in the community which have helped qualify them for LEND.

In some cases starting with short or medium internships might be helpful as a way to get family member started.

Programs can also start by doing an asset map for health financial community resources and share

this information with your department to see if it can help activate resources.

In thinking about recruitment for family trainees recruitment can include parent professionals in the community and community agencies. Support group leaders, people who have tended partners and policy making. Parents serve on disability -related advisory boards and boards of directors.

It has always been very important in the family disciplines to really represent the diversity of our communities. And so the idea of networking with minorities serving support organizations can help increase diversity.

In some cases you may be able to recruit undocumented families through connections in the community, and specifically partnerships with the organization as opposed to providing a stipend directly to the family member. You also need to be aware of language barriers in these instances.

Take advantage of existing materials. There are many of us who have been doing this for a very long time and we have noticed things that were needed to support our trainees or to fill possible gaps. Some examples are things that we have created here at the California LEND including pathways to LEND which is a pre-discipline or pin Tatian we hold during the summer -- pre-discipline orientation to help trainees learn some of the tasks they are going to be asked to do in the program.

We have all will -- also created the parent portfolio which is a tool for gathering relevant family experience to develop a family discipline resume. Too often we found what we asked people to submit their resume we might find out that the work they did working in a bank, but it would not necessarily tell us about their family support or assistance change leadership experience.

It is important to provide stipends for family trainees in the same way we provide stipends for other disciplines. If a family training has been working as a parent professional or they are currently working you can document how the LEND participation or your programs participation of the benefit their employer. I know I have written letters in many cases, and frequently those potential trainees are able to get release time their job that is paid because the agency really sees that it is going to benefit them as much as it is going to benefit the individual training.

It's important to know that family trainees may need additional support or mentoring from their discipline supervisors. But when we talked with LEND programs we heard that most do not need to modify their curriculum. You might consider having a longer training.. For example, having your family trainees go through your program over two year period instead of the standard one year., And again, this is in recognition of the fact that they had very full plates and also they may be having more academic demands just because they have been out of school that long.

You might want to use the ITAC toolbox for additional implementation strategies.

So, barriers. We want to talk about barriers because they come up. For example, in some programs they really do not necessarily understand the value of having family trainees. Not all faculty may be onboard. You might want to talk with programs that are currently including family members as trainees.

You may also find that family trainees feel intimidated by trainees for professional disciplines. They may need emotional and/or academic support to help them really feel comfortable and have specific opportunities for their voices to be heard.

Since family trainees may not have the same academic preparation as other disciplines, again, consider the idea of pretraining in your program and you can use pathways to LEND as your model. Again, family members may have very full plates so consider those opportunities for shorter-term participation or longer training term.

You can almost place money on it. Family trainees may have a crisis or conflicting demands during their training. We like to do some preplanning for possible barriers to participation. One model that we use in our program is something that is based on a fair plan that is used on the group self-help during through the arthritis foundation. When you have lupus a flare isn't a possibility it something you know is going to happen and we want to be prepared in advance.

We do something similar and we look at what are possible things that might prevent a person being able to participate in LEND or two assignments, and they come up with their plan be beforehand. -- Plan B beforehand.

Is the slide changing, Emma? There we go. Evaluating success. First of all, it is important to recognize that incorporating family members as training might be a four or five step process. You want to look at both readiness, and then as you are actually doing the program success.

Evaluating the success of your trainees can include standard assessments used for all trainees. You also want to think of identification of areas of challenge for family trainees, and evaluate the success of family trainees specific strategies. You also want to look at the evaluation of training recruitment and applicants, inclusion of family members may require different recruitment strategies than those used by other disciplines.

We have provided a number of resources and these are all available to you. I also wanted to, just in this section, with a quote from one of the fellows on the impact of family trainees. They said, "It was an indelible impact. I have learned so much from family fellows during my time with LEND but will remain

in touch with them far past my training time and will carry their perspectives with me forever."

We are going to open this up to questions now.

SPEAKER:

This is Anna. Go ahead and submit your questions in the chat box. Feel free to come off of muse and ask your questions verbally. While we are doing that we are going to switch the slide deck from being shown on my desktop to Maureen's since I'm having internet issues. No worries. Submit your questions and we will continue with the presentation.

SPEAKER:

Hi, Fran. Excellent presentation so thank you so much. My question is we have our family trainees this is what we have done historically, come for one year. I do know there are other, as you said, who maybe have already in place two-year training programs. When you are talking about the plan and be that you mentioned might that be a plan B that they come up with when the trainee says there's knowing I can finish this in one year with what I have to deal with at home and then the demands of the curriculum and then move it to two years. What might that look like?

FRAN D GOLDFARB:

There are many Plan B. It ranges from something as simple as our LEND starts at 8 AM and you have to get your kids to school how are you going to get here in time? And then our trainees are really doing their planning to say, OK, now I have made arrangements for my kids to get to school or what do I do if my in-home supportive services provider does not show up? How am I still going to get to LEND? Those are some of the things that we are talking about.

What you are talking about, and our decision to switch to a two-year program, really came from the fact that we had so many fellows go through the program on a one-year track and then just not be able to get everything done and they came to us and said, can we do two years?

We said, yes, but we also said this is happening often enough that we really need to do something about this. What we were developing pathways to LEND we did focus with all of our graduates and one of the things that they really recommended is just do it as two years for everyone. And then it takes all of the pressure off of asking for that.

In fact we had one trainee, she was fabulous, absolutely fabulous, but English was very much or second language. She ended up doing the program over three years. And it worked out just fine. So, Plan B can be very small or very big.

SPEAKER:

Thank you.

FRAN D GOLDFARB:

Are there any other questions? So, Emma are we ready to move on to part B? Or Part C?

SPEAKER:

We are indeed.

FRAN D GOLDFARB:

We are going to be talking now about family members participating in program planning, implementation, and evaluation.

So, when we are talking about this we are saying that this type of involvement really involves family input at all stages of program design. It can include having family members serving as part of a planning team, designing models for implementation and or participating in program evaluation and subsequent revision.

Yesterday Wanda (Name) talked about the value of family research and emphasized the importance of front and involvement. We really, really second that. We do not just want to tax the family on at the end and say to them, did we come up with a good plan? Or one that really works?

Get families involved from the absolute beginning. Family participants may be members of the program faculty. They could be members of your advisory Board, past trainees and other community members.

So, this type of family involvement is really best for programs that, first of all, value family input at all levels. Who have access to family members who are familiar with the program. Programs that are writing initial or renewal applications that may not have family members as faculty or staff so they really do want to return to your community to get that family input.

You may be considering adding family members as faculty, staff and/or trainees. Or that you are interested in evaluating the family centredness of your program.

So, in discussing the need for family participation we know that family centredness is really a core value of all maternal child health training programs. And is considered a fundamental competency. Programs really need to seek to develop faintly centred -- family centred programs logically. If you are looking to be family centred you have to demonstrate those values and include family in that discussion.

So, family centredness by definition is a partnership. It should exist at all levels. It should exist at the systems level, at the individual programmatic level, and then at the individual level as well. So, when you are working directly with families, when you are developing programs, and when you really participate in systems change.

Family members participating in program planning, communication and evaluation occur at the programmatic levels. When you are putting together your program you want to get that family input. Family input is necessary to a family centred problem. If you are saying, G our program just isn't family centred enough, or isn't family centred health without that family input and it is difficult to get an authentic response to that question.

As I said, family centred care will require a component for all maternal child health trainees with an expectation that all support programs demonstrate 100% family centred care and that is in place since 2008.

It is also expected that families have a role in planning, and that they are not just tack down at the end or just included in the proposed training faculty.

A discussion of benefits. I think I am getting Lupe even though I am three hours earlier that the East Coast folks.

It allows for family voice to be fully integrated and this increases the likelihood of program success. We are also modelling authentic family involvement to other faculty and staff and trainees. You will hear the term authentic family involvement over and over again because, in fact, that's what we are looking for.

We note that family participation increases the likelihood that programs are mindful of cultural considerations. In that family involvement can transform your capacity for family centred care.

And according to the Colorado Department of Public Health and environment their fast facts on family participation. It improves estate and community needs assessment process, it increases the number of effective family advisors within community programs, and reduces the perpetuation of a narrow scope of work in grant proposals.

So, some strategies for implementation. First of all, it is important to recognize that not all families are going to come to the table with the same level of knowledge and skills that other members may have. It is important to provide training and support for family members to help prepare them for meetings, and also debrief after meetings.

It is a good idea to work with existing family organizations such as Family Voices, or family resource centres with you may have more family members participating who might have more skills or background.

Think about providing ladders of involvement. So, people do not necessarily have to commit to a three-year term or to a very high level of involvement, but maybe allow people to dip their toe in, help them develop skills to participate in program planning implementation and evaluation.

Involve those LEND family discipline graduates. They are a fabulous source of participants. As well as looking at graduates, and partners in policymaking if you have a program in your state. If your state does not have one you might consider starting a partners in policymaking.

Offer childcare. One of the barriers to people participating is that they do not have childcare services available. And it should not cost people money to help you with your program.

Think about providing translated materials and interpretation at meetings if it is needed. Too often we just say, we will only involve people who speak English. But English speakers may not be the only ones with something important to share.

Involve family members and self advocates in reviewing training applications and interviewing trainees. Include family members and site visits. Involve family members in reviewing publications. Ask Mentor parents to review their experience and the trainee that they Mentor and compile the data for the benefit of future trainees.

We have other ideas for implementation that are available in the family centred care section of the ITAC toolbox.

So, addressing barriers. First of all, one of the big barriers, attitudinal barriers, which can be demonstrated by the faculty or community. This can be addressed by talking with programs that currently involve family members to demonstrate potential for success. Also it is important that to recruit high-quality family leaders you have to have a clear understanding of what their role will be and the importance of their involvement and it really needs to be articulated and communicated, and it is also very important to continue to use their input because there is nothing more frustrating than participating in planning and seeing that you have not necessarily made an impact.

We want to avoid tokenism at all costs. That means that families may be training and support if they are to actively participate. This may require additional faculty or staff time.

We also know that families should represent their community, programs should not only include those

who are easy to include, because this may result in cultural linguistic barriers to inclusion. Be prepared to engage these cultural and linguistic competency training and required translation of materials and provide interpretation at meetings as needed.

It is also important to remember that involving families can result in logistical barriers. Programs need to be prepared to be flexible in meeting times, locations and modalities. Consider options for remote, or as we have learned, you can do asynchronous participation.

Too often we tend to think about meetings within the realm of the workday. It is important to remember that family members also may have their workday. And the only time they may be available maybe late afternoons, evenings, weekends.

So, in looking at evaluating success we have provided you with a number of resources that are available through Family Voices, from the Institute of family, centre, care. As well as their self-assessment tools as well as tools for measuring family centredness and family partnership.

And again we have provided you with a number of resources for implementation and these are all available to you and to help you support your program as you move forward with it.

And with that I think we are going to look at some time for questions again. We can take questions either from this section, or from the families as trainees if there are any that come up.

OK, let's see we will take about another minute for questions.

**SPEAKER:**

This is Emma. I want to remind folks that the slides are available online. The link has been shared in the chat a few times. All of the wonderful resources that Fran and we have provided you with have been hyperlinked and although slides. If you would like to browse some of them now, I know she referenced the ITAC toolbox a number of times, I will share that in the chat right now so you can play around in there and explore some of the wonderful strategies that she referenced.

**SPEAKER:**

Fran, this is Stephanie. I don't have a question but I want to say thank you to you. I know that there have been others along the way with you that have planned this discipline for so many of us coming up behind you, and will continue to come up behind you, but you are amazing. You have been my mentor the last four years. I absolutely love and adore you. I appreciate everything you have given to this at that you have shared with me and so many others. Just want to say that.

**FRAN D GOLDFARB:**

Thank you. Thank you so much. Please know how mutual those feelings are. It looks like there are not other questions so before we give you about 10 minutes of your day back I just want to do a shout out to the LEND family discipline network. This is a wonderful team to work with. If you are not a part of this we do not limit the involvement to LEND programs, or to LEND family T. -- Faculty. Anytime someone is interested there welcome to participate.

And then I wanted to also do a little thank you to Ben Kaufman who was the one who conceived the idea of putting together a webinar series on Fabric and not Fringe and say thank you for that which you provided as well as our AUCD team who absolutely made this webinar series possible. So, thank you all and go enjoy your afternoon.

SPEAKER:

Thank you, everyone. I will stay on for a little bit if anyone has questions or concerns. Please remember to fill out the evaluation that was shared in the chat box, but you can also scan the QR code you see in full view. We would love to hear your feedback and see you future webinars. Thanks so much.

SPEAKER:

The recording has stopped.

SPEAKER:

I'm sorry, Karen I didn't catch that.

SPEAKER:

When is this going to be posted on the AUCD website?

SPEAKER:

This will be up in about a week. Next Tuesday.

SPEAKER:

Thank you.

FRAN D GOLDFARB:

And the first two have been posted already so they are available for viewing.

SPEAKER:

Looks like the majority of folks have left.

FRAN D GOLDFARB:

I think we are good. Thanks, Emma.

SPEAKER:

Great job as always.

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