

Live Captioning by Ai-Media

MARK SMITH:

Looks good.

JACKIE CYZIA:

Hi and welcome to the 2021 family discipline network summit. We will just be waiting a few minutes as more people join.

SPEAKER:

Recording in progress.

JACKIE CYZIA:

Hello and welcome to those who are joining us. We have more than 150 people registered for today which is very exciting. We will just wait a few minutes to allow people to join the meeting.

As we are waiting please feel free to introduce yourself in the chat. I am using a few giving their title and where they are coming from.

I'm seeing trainees, family, faculty. Welcome. I'm just going to give it two more minutes as we wait for people to join.

If you are just joining feel free to introduce yourself in the chat as we are waiting to get started.

Great. We will give it one more minute.

JACKIE CYZIA:

Alright. Welcome everyone to the 2021 LAND Family Discipline Network Summit. I am a Jackie Cyzia and I am the senior manager here at AUCD. I am very happy for you to be here today.

Due to some technical issues that happened earlier I will be turning my video off while I am speaking so that we can make sure that my voice is going through clearly. Next slide, please.

We are very excited to have you today, today is our first day of the summit. We have another day tomorrow where you will be joining us in the afternoon. The summit is really designed for LAND leaders and trainees such as yourself in the field of family support to address critical questions and addressing equity for families in their programs and life beyond the trainee shift.

We thank you for being here today. We have some amazing workshops and activities.

Here some housekeeping items. Please make sure your name is displayed correctly in the participant list. You may also include your program or organization and preferred pronouns. An example would be

Jackie Cyzia, AUCD, and by pronounce or she/her.

If you're not sure how to do this you can hover over your name in the participant box, select "more," and select "rename." Please stay muted unless you are speaking. Closed captioning is available at the bottom of your screen, you should see a CC button and you can click on it for life captioning.

As many of you have already done so please use the chat box to introduce yourself. Please include your name, program, where you are coming from. We want to have a sense of you is joining us here today. As I mentioned earlier, we have over 150 people registered for today's meeting and I'm sure more will be joining us shortly. Next slide.

Before we get started I wanted to give a quick introduction to ITAC for people who are less familiar with that. It stands for the interdisciplinary technical assistance Center for autism and and develop mental disability. The purpose is to help improve the help of families, infants, children, and adolescents who have or are at risk for developing autism and other develop mental disabilities.

This is really by providing technical assistance to these training programs such as LAND which I am sure you are already familiar with, it stands for Leadership, education, neuro developmental programs and also the DBP programs. We also provide staff support to the LEND family network.

We make it short... We haven't really work together to address issues unique to family inclusion. And members represent all BLEND programs there at the country and bring their experience and advisory capacities in numerous areas. Today's first workshop we will go into more of the history and work of the LFDN and we work bimonthly on Wednesdays at 2 PM Eastern time. Our next meeting will be October 14.

If you are not currently on the (indiscernible), or if you have questions about the LFDN you can contact Jeanette Cordova and we will put her email address in the chat.

That leads perfectly to the next Segway. We are welcoming Jeanette Cordova! Jeanette is our new program manager, she is also the new staff liaison for the LFDN and I will hand it over to her to give a quick introduction.

**SPEAKER:**

Hi everyone, I am Jeanette Cordova, I am a graduate from the LEND fellowship in JFK partners University of Colorado, and having gone through that program it is just an amazing program. I am a parent of a 19-year-old who was born with down syndrome.

In addition to that I am a caregiver for my mom. But I am also just really happy to be here, to be supporting the LFDN however I am needed. Thank you so much.

**JACKIE CYZIA:**

Thank you Jeanette, we are happy to have you on board. Next slide, please.

Just a quick overview of today's schedule. We have a welcome and introductions right now, we will have after introductions our first workshop which is the history of the LFDN, we will take a quick break and then go into workshop B which is working on diversity and inclusion into family discipline including reflections and lessons learned.

We will have another quick break and then we will go into a virtual poster session which is an opportunity to learn about family programs in LEND. At the end we will have our closing and a happy hour which is of course optional but we hope you will be able to join us. Next slide, please.

I wanted to make sure you all knew where to find the event of materials. We have on the ITAC website which will be sure to put on the chat is for the event page for this summit, we have a series of materials including the final agenda, the history of the LFDN, we also have another materials including a presentation on a white paper earlier this year. This is where people put the slides as well as the recordings and other event materials one week after the event.

Make sure to check back, we will also send an email after today with that reminder. Throughout this summitry will be using jam board throughout the meeting. I know Maureen Johnson has been putting links for you and she will also put the link to the jam board.

For those of you less familiar with it it is a collaborative digital whiteboard that makes it easy to share ideas in real time. We will put it in the link and it is for you to access throughout the meeting. We will of course provide reminders as well.

There are two prompts we have for you. One is, "name one thing you will take away from the summit and bring back to your LEND program."

The second prompt is "where will you go from here?" This is what we should focus on the 2021 and 2022 academic year. As a Fran Goldberg will go through quickly we have a lot going on and who want to hear from you but we should focus on.

For those of you who are less familiar with Jam Board, if you could go to the next slide, please, thank you. Just a quick note on how to use it. On the left slide is a couple of symbols and you will notice that the only one you really need to pay attention to is the sticky note which has the purple arrow to the left of it.

If you click on the sticky note you will see that there will be a prompt and they are multicolor's you can pick whatever color that speaks to you. You can write your prompt or answer to the prompt. For this one "name one thing you will take away, close quote I have the example of "ideas for family mentorship..." If you click save it will appear on the Jam Board.

If you have any troubles you can contact me directly.

As we are starting the summer to want to have better ideas about who is here. I will launch a quick poll

if you could just take a minute or two to answer it. Can you see it?

SPEAKER:

This is Mark, just the results page. Not the pole itself.

JACKIE CYZIA:

OK, she can see the slide, Mark?

SPEAKER:

Jackie, I think it went right from asking and went straight to the results.

JACKIE CYZIA:

Oh, it is working now.

SPEAKER:

Can you check all?

JACKIE CYZIA:

Yes, you can click all that applies. Some of you might be LEND faculty etc. 20 more seconds.

OK, I think we can share the results of the survey. So, we see some current trainees, former trainees, lots of LE and the family faculty and staff. A few training directors. Some of the faculty and staff. Some other from the training programs. And family support professionals. And of course, our federal partners. So, wonderful. Thank you for being here.

You can go to the next slide. The next poll. And we will see if we can love this correctly. Let me know if you cannot see. How many years have you been associated with EMD? Some of this -- you this might be your first year. Or you may have been involved for a very long time.

Great, we will get a 10 more seconds. Great, some 28% if you have be less than one year. (indiscernible) and we have a couple, 8% that have been involved for 11 to 15 or 16+ years, but is amazing. Thank you for joining us!

Great, next slide. I am happy to introduce law in Mammoth, Director for the division of MCH workforce development. She is here today to provide a quick welcome. Thank you for being here today.

LAUREN RAMOS:

It is my delight to be had to welcome you. What opportunity to connect with family leaders, and to see so many trainees, as part of the group today, but well at all of the family support you are here today.

I wanted to eventually share my enthusiasm with you, or how much you are trailblazers. At a it, you have really helped to it elevate the value of family (indiscernible) in particular, in academic settings, and in clinical practice. You are having a significant impact Wendy Kelley MD program across the network, and you are really helping to strengthen family leadership, and the family discipline across all

interdisciplinary training programs.

The resources that you produce such as the fabric white paper, the LEND family involvement that make these webinars of all influenced programs in the broader field of family leadership. And as you saw in our recent guidance, you are influencing the LEND program directly.

The family discipline, if you didn't notice, have become of the Lord disciplines across the network. And this is no doubt because of your leadership and commitment to supporting family members, as well as (indiscernible) internal health, and as about it at critical members of the care team. I want to thank a few family members in particular. But, Fran for her years of leadership, encouragement and with them. Kristin and Jonna for leaving the summit. The entire committee.

I also wanted to submit my thanks to AUCD for their support for the network, and to our project officers, Robin Peter, carbon and that back. They make sure the family members have a voice at a place in our programs. I am so close to be here over the course of this meeting, and they (indiscernible) the time, the energy and effort that you put to coming together, and really spreading the lessons learned and helping us to continue to grow and strengthen family discipline.

Thank you so much. And Jackie, I will turn it back over to you.

**SPEAKER:**

Thank you so much. Next, please? Wonderful. Well, now we would like to hear from you about the reason why we are here today, at the people you thought of the summit. And one of the main reasons why all of us our gambit. So without further ado, I would like to introduce Kristin Flott, and Jonna Mulvaney, who are from Nebraska and Rhode Island, and I will give a critical introduction to himself.

**KRISTIN FLOTT:**

Thank you so much. Very much appreciated. I thank you for taking time out of your busy schedule. I am the campus and community outreach coordinator, Director of family faculty at the (unknown name) Meyer Institute in Nebraska, and the Nebraska LEND program. My partner in crime is...

**JONNA MULVANEY:**

I am the patient and family centred care, quoted in Rhode Island. I am also be family discipline a mentor for our Rhode Island LEND. I am very happy to be here, thank you everybody for joining us.

**KRISTIN FLOTT:**

Thank you everyone for being here, and welcome. Welcome to the summit.

**JONNA MULVANEY:**

We will go to the next slide, please. Katie tells Elizabeth more about how the summit came to me?

**KRISTIN FLOTT:**

Before COVID-19, I started to realize that we were only meeting as a family discipline network for one hour out of a 3 to 4 day period. And, as a former trainee, as well as a parent and family faculty, that

just was not enough. I mean, one hour with these amazing family members, and faculty, and all of the things that I could learn, and wanted to upload, across the network, and I had to squeeze it into one hour.

And so, I just started to think "I would really like to spend more time with these folks." And so I talked to Ben Hoffman, who is an employee, and we started to plot and plan on how to have a summit in person, the day before the entire AUCD annual conference will even happen. So, my idea was to actually have us all come to Washington DC, a day early, and have maybe 24 hours for those of us that wanted to spend that much time together, plotting and planning as to what we can do together to continue to build this amazing network that is those that have come before us have done such a great job of building.

And so, unfortunately COVID-19 happened. So now we're bringing this to you virtually. And with the assistance of an entire group of people that I will introduce in a few minutes, we were able to bring this to, like I said, a virtual platform, and hopefully share those ideas and network and opportunities moving forward.

So, kind of a get to know you. So, I welcome you, and I hope that you will sit back and anticipate. And enjoy yourself. I feel like you are part of the family.

So, the purpose of the summit, like I already talked about, was that we could foster collaborations, and have that collaborative environment as well as providing and receiving mentorship in the family discipline. I hope that we are able to continue to develop and define the relevant family resources, and share best practices and identify opportunities for going the community. Through animal

RENEE FOLZENLOGEN:

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JONNA MULVANEY:

So our learning objectives are that by the end of this summit, we will be able to understand and recognize the value of a family as a professional discipline. I think that is really why we are here. We want to strengthen and energize the existing developments, and foster the new relationship to happen here, and maybe in the future as well. With the support of the professionals outside of the (indiscernible).

So, here is where all the magic happened.

KRISTIN FLOTT:

I want to give a big shout out to the climate committee, Stephanie Coleman, (unknown name), Wanda Felty, Fran Goldfarb, to Morocco, Angela Hornsby, Jonna Mulvaney, and Mark Smith. And those are just some of the LNG -- every MD faculty. And this would not be possible without our panelists, the poster presenters, Emma foxy was a former employee, and AUCD as well as entity HB.

And to all of you. I really appreciate you being here today, and taking time out of your busy day to be

with us. I am so glad that you are here.

JONNA MULVANEY:

Thank you. I will introduce the new programs can quickly, so we have some new book of. The University of Texas at Austin, downstate, Georgetown University, children's National research Institute, the University of Judea, University of Kentucky, University of California San Diego. Thank you, and welcome everybody.

KRISTIN FLOTT:

Alright! I know we are running a couple of minutes later we will get back on schedule here. So, workshop letter a is our history of the LFDN and the facilitators are going to be Wanda Felty, and Fran Goldfarb. I will introduce himself. Welcome, I thank you so much again here.

FRAN GOLDFARB:

Thank you so much. So, if you get out. But now we want to talk a little bit about where we came from. So, that afternoon, I told Bob, and of the family support faculty for the California program in Los Angeles. I am also the chair of the LFDN, and a member of the old stuff. I am one of the 16+ people.

As of thinking back, it all started in a room. It was just an ordinary meeting room. At the 2004 AUCD annual meeting. It was an ordinary room, but inside it, something extraordinary was happening. We were brought together for the first time, by Elaine Audubon, from the (unknown name) in peculiar. The first time that the faculty had gotten together, and met.

I do not remember how many people were there, but it was a bunch. The room was filled with people, and excitement. (indiscernible) something. And then colleagues who were similar to me.

In 2004, we launched our first survey, and not to survey ourselves. And, this gathered information about family involvement in our programs, and this was the beginning. Following on the heels, we were designated as the MCHB discipline of the year. Only the second and be so designated. Scheduled to have a Summit in 2005, at this initial meeting led to the Summit planning group, and we became closer.

After a result of the Summit, we fought to work with. Each of whom produced an important document. Promising practices in family mentorship, and also the MDM the family discipline conferences. The group finished artwork, but wanted to continue with the relationship, and so, in 2006, the network was born.

I took on the task of chairing the group, is history. Also, our history is contained in the history of the discipline network document. This is available on the AUCD website. So I will hand it over to Wanda Felty from Oklahoma, you will be motivated to our panel of original members, I will move to being a panelist. Wonder!

WANDA FELTY:

Thank you Frank. Firstly I want to say that it is my honor and privilege to introduce this group of

panelists.

I met them in 2009 and they have been my mentors since that moment. So, it is an honor and privilege. Fran almost solely introduction for her but I will read what I have anyways. Bear with me as I read her introduction, I thought about skipping it but you have to know about these people before said hearing them talk. Also, wish me luck when I am moderating. You'll understand why in a minute.

Fran Goldfarb was a family support system director at the California Lend as well as at the USC University Center for develop mental disabilities, research, education, and services at Children's Hospital, Los Angeles.

She shares the LEND family network and is the (indiscernible) for the family survey. We do like to serve! Most importantly, she is the parent of a young adult with develop mental disabilities and other psychiatric disabilities. Welcome Fran.

Barbara Levitz retired in 2019 after a 30 year career with a Westchester Institute for human develop meant which is in the land of New York. She served at the director of family partnership training and in various other leadership roles advocating for disability issues at local, state, and national levels. Glad you are here, Barbara.

Jana Moss is the parent of two adult children with develop mental disabilities, she began her advocacy by testifying before the national education committee on special education. She worked for the Oklahoma parent center as a trainer before moving to that or a U center for excellence and developmental disability. She was also core faculty for the Oklahoma Land and was my mentor when I came into this.

Paula Petrie is a – oh, welcome Jan. I forgot to mention because you were my mentor.

Paula is a author with large generative experience is that she reasons her teaching. In her healing journey from the lens of her daughter, Doctor Petry found alternative approaches to health and wellness that letter to serve as the wellness director at the holistic K28 school in Miami, Florida. There she teaches the medicine wheel curriculum, her memoir, 'a mother's courage to awaken hope and inspiration: for my daughter's journey to the afterlife' is hurt story about love and the healing quest and initiative. So glad you are here, Paula.

Mark Smith is a parent and sibling of those with develop mental disability. He currently serves as the associate director at the Nebraska center for disabilities at the Monroe Institute. He has served more than 45 years and disability services and works to promote systems improvements and disability services and support. Mark and his family live in Omaha, Nebraska and they enjoy cycling, going for long walks with his dogs, and playing music. So glad you are here, Mark.

Those are our panelists for today. Welcome all of you and thank you so much for being here and I have to tell you, as a family faculty I cannot tell you how much I appreciate you paving the way for all of us. So, welcome.

So, I am going to open this up. I have good questions that I am going to ask and I will call on one –

SPEAKER:

(indiscernible)

WANDA FELTY:

Others attack on if you feel like you can add. The first one I will ask is to Barbara. Tell us about the beginnings of the family discipline at LEND. Take us back there. You are on mute, Barbara. We follow directions and then we –

BARBARA LEVITZ:

There we go, how's that? Thank you, Wanda. Thank you for the introductions.

This is a really exciting time and I am happy to reflect back to so many wonderful years working together with everyone but the beginning of family discipline at the Westchester Institute for family development in New York where I was located is actually from 1990 which is a little more than 30 years ago.

Parents were hired as professional staff on teams that were developing regional early intervention services as well as providing statewide training and advisement, particularly in the area of family centered practices and my son Mitchell was born with sound -- down syndrome and is now 50 years old.

So, between my experiences as a parenting Mitchell and a trained special education teacher, and someone who started a down syndrome parent support group who had worked with the Institute over so many years as a volunteer, it was very fortunate opportunity to be recruited for this role along with other family members as well as other organizations and children with other kinds of disabilities.

So, 1990 again, we started with being professionals on staff and early intervention training. From there, in 1993, we established a family resource Center using and creating a new model which was employing family members of children with disabilities as service coordinators for other families. We did this primarily in early intervention and then moved it to mediate service coordination.

The second aspect -- aspect in terms of rules for families was also in coordinating, setting up and coordinating a parent to parent program which later we were able to expand to fund peer to peer in New York State.

Those are two very important things. In 1995, as of the program director for the family resource Center I became the LEND core faculty and had an implement with the New York medical College faculty there.

So, the process was developing, teaching, coordinating training sessions relating to family topics. That quickly evolved into a very comprehensive, full curriculum model on family partnerships.

What worked so well for us at the time, in terms of family discipline in many different roles, was that because we had the peer to peer program and the parent service coordination program. It enabled us to have a very diverse network of families who were available to both mentor families over the years as well as participate as presenters for our LEND sessions.

It also provided the opportunity to recruit families as trainees and we began that in the year 2000. Another piece of it was having the opportunity as a Fran had mentioned, to present this model. We started attending AUCD meetings and better the opportunity to connect to other people. A little history (Laughs).

WANDA FELTY:

Barbara, first of all from Oklahoma I am a little jealous because you just open the door and it sounds like y'all ran through the door and did not slow down. I really appreciate that and when the door opened it sounds like you had every opportunity to bring it and then you brought it to AUCD.

Do any of the other panelists have a completely opposite... The door was not quite opened, anything extra like that?

PAULA PETRY:

I guess we opened similar to Barbara and that it was in 1994 I was hired by the Center for Child Development in an assistant role and not his family faculty per se. In reflecting back into thinking that our early days and asking what it was like, I was listening to a podcast and it was about a goddess (unknown name). This is what it was like, I don't want to say in the LEND program because I will say more about that.

But the goddess in this mythology tells us that she was the only goddess not to be invited to a very important wedding. She showed up and I think in the days of the 80s and 90s I think to some degree it was a little bit like that, right? We appeared and the myth goes that she showed up and created chaos.

I think we created chaos, I think we still have a role as family discipline, I resigned in 2006 and I have done other things, but I still believe in the strength of family discipline. So, we turned up the heat and created chaos.

She became something of a patron saint of chaos and creation. Let me see Sinemet chaotic creation because I think this is really what family member's have done over these decades. She says, "I am chaos. I am the substance from which your artists and scientists build rhythms. I am alive, and I tell you that you are free."

So, is it the chaos began in the 80s and 90s, I suggest families coming into the discipline and into LEND and AUCD, I came in through that door. We brought in that tension that I think is always important, not too great chaos.

We began to harmonize in that system as we are listened to and everything we are able to do can and continue to do is able to happen. In the LEND program that leads the ADD program in 1974 and I met the training director and the unveiling of the red book, do you remember the red book and the family centered care conference in Washington DC?

We had met there and I was the parent to parent in Miami so I had been in a lot of doors creating a little bit of chaos, I think. It helped pass legislation and I was on the parent research organization. Coming into the program and into the mailman center, there was such appreciation and she has passed away now but I had such a wonderful mentor.

So, we focus on many different things, and one of the beautiful things was understanding the family perspective and it was a 12 hour module for pediatric residents and then we brought in other families to teach that. There were many things that we were able to accomplish.

Within that we matched parents with pediatric residents to make home visits, and I remember setting up grand rounds and sharing some preliminary data, we ended up doing a full research study on that.

WANDA FELTY:

Very good. Again, another doorway that we can walk through, I love the example of the chaotic, while we do not intend to bring chaos sometimes partnering with people with lived experience can kind of tilted the boat in little bit. Just tilted and it lifts up straight.

I'm going to post the next question to Jan. Thinking back to the discipline at the year Summit in 2005, what was significant about that meeting? Thinking back to that meeting in 2005.

JAN MOSS:

Am I on?

WANDA FELTY:

Yes ma'am.

JAN MOSS:

Good. It was... Enlightening to say the very least. I was thrilled course to get to meet with everyone, and I was thrilled to hear the experience of being a family member discussed as a discipline. I started advocacy before the laws were passed and one of the things that was just kind of tea for me is that I started trying to find other family members from the very beginning who were having some of the experiences that I was having.

I was finally able to realize that on a level I have never had before. So, it was... Just, mind opening. And mind blowing. And working on the documents, having family experienced as a discipline was very difficult, in state, for some time. And slowly but surely, as our LEND faculty began to have family members come and speak, family members to come and teach, which is almost unheard of here, we began all of this, and I always asked the same question.

I would say "Well, this is true of me. Is it true of others? And if it is, you are the others and how can we all tap into our collective experiences?" And it just made you so white. Some of the things that the family were able to share, I remember one family member who talked about their and being (indiscernible) and had never had a single infection. The medical staff could not believe it, but she had. The kind of information that came out in many many ways.

My daughter, and (unknown name) now, and that gives you some idea of how old I am... Jennifer was deaf, and also has cerebral palsy and a number of other learning disabilities. And, even in the community for the hearing impaired, she was sectioned out, because she had a physical disability.

So learning the culture of disability, was just an exploration all on its own. Did that answer the question? Or did I just ramble on?

WANDA FELTY:

Good, and he took me down another path but it does lead to the conversation of how we tend to segregate differences, when we are actually more like. And that if the family discipline.

So, I am going to move to the next question, and that anybody else was to add anything else to that closer to the 2005 Summit.

BARBARA LEVITZ:

I just want to add one thing, and that is that making that connection with our families, and one of the fact that

LECTURER:

Family discipline network have been given for years if mentoring program. With they are new programs, or just sharing and exchanging information. At my son of Mitchell and I had the opportunity to join in Denmark and other people in Tulsa, talking about family support.

And it is just another way of bonding, and they were out in Denver, with some family faculty. It is just being a great opportunity that this network has created.

FRAN GOLDFARB:

(indiscernible)

SPEAKER:

It was a wonderful opportunity to get to visit with you all at that time. And it is just did with me all easy.

FRAN GOLDFARB:

When we were meeting, the back direct also meeting in a separate room. At every few minutes, one or two or three LEND directors sneak into the back of our room, to see what was going on.

And, you know, we fought like we were sort of subversive. And it felt really nice that a if of a large late middle aged women were so frightening. And when (unknown name) talks about chaos, I think that

yes, we did shake things up, and we were seen as agents of change.

WANDA FELTY:

I love it. And isn't that what family happy doing all along? We just got a title and a discipline behind us. I love it. (unknown name), did you have something you wanted to add?

MARK SMITH:

I just wanted to say that I am not a middle-aged woman but that is OK. I related to this group, I started with our program about 2000, but I just was recalling back to that first meeting and that first meeting with the panel. And lots of other... (indiscernible) we really believed in the power of family bonds together.

And so I just jumped at the chance to go the 2005 meeting, Nesbitt said about the amount of energy in that room, I can verify. It is absolutely true, it is just amazing. It is like everybody happy waiting just the opportunity. And of course, we have (unknown name), the former AUCD Director, and (unknown name), and they are saying let's go get them.

And with my background, they had me at hello. And then the chance to get to work with people like (unknown name), was just amazing. And I came back just ready, ready to vote. It still took a little while, but I have also learned the lesson of the system. I just do not quit. It will not happen right away, but it will happen because I am just going to keep pushing.

And Barbara imagine her travels, and I got in trouble with her as well. And yes, it was really cool opportunity imagine from this all around this idea of family voices, coming together, you know, to work on the anthem of emphasizing against the power and the impact of that company working together, and passing it on. And having the really fortunate opportunity to work with a lot of new folks coming in over the years.

It is more fun that it is work, believe me. It has been too long.

FRAN GOLDFARB:

It is good to see you too.

WANDA FELTY:

You are cracking me up. The when you sit persistent, it really is that patience and persistence. But that is what family have been doing all alone.

OK, I have got three more questions that I have got to get from, and I really want to hear your knowledge from these questions. So, I am going to move to the next four. What changes have you seen in LEND family disappointed 2005? So just tell me something that has changed from this first time, to the last time that you were with (unknown name), or even (unknown name).

FRAN GOLDFARB:

I think probably the biggest change is that we are no longer the exception. In the beginning, the one

exception. Family is a required part of LEND program. And so, I think that is so cool. And we know that the family discipline, they say if you have seen one

ED SIMLER:

, You are the one and back. Well, if you have seen one family discipline, you have seen one family discipline.

And it is Diverse at the LEND programs, but every lead program has family involvement, in some way. And our trainees are expected to suspense in LEND, and we have to explain our discipline and also our place less and less. Because it has been, more than normal.

MARK SMITH:

A lot of the other disciplines at the very beginning like "Why are you here?" And then we started to talk, and he stopped asking that question very quickly. And I thought it to have student mining up outside my door, basketball about this. That family centred for you were talking about the everyday. This would really help me in my practice, going forward. It was just an immediate shift.

SPEAKER:

I want to throw in the part that MCH played in securing funding. That was a huge issue. One of the things that always came up is that without having a college education, while we fit enough? Or smart enough? Two the comical faculty in so many areas?

And I think that the outstanding families that we were able to introduce, each of our lands, proved that. And I was especially, because I introduced Wanda Felty.

WANDA FELTY:

Thank you!

BARBARA LEVITZ:

I just want to add that another element of the that we have seen in all of our programs, but has really increased number of family members, whether they are siblings, parents, individuals difficulties, and all of the family group, that more people are serving in leadership roles, on staff.

Many of our land trainees are joining and moving into staff positions and samples. And it is very desirable. So we start with our Institute at the percentage of family members who actually employed at Institute is quite large. It is the vast majority. So it is again, that sense of the value of having families in the role, and staff and partners.

WANDA FELTY:

I like that. That really is enlightening, because I knew that thank you put it into words. Carla, I want to offer you an opportunity to respond if you want or I can go up expression.

PAULA PETRY:

In terms of current activity in the LEND, I have not been directly involved. But I know that the position

has primarily been over the years, by an individual with a disability, with a focus on leadership. So they do leadership in three different populations, high school, general community leadership, always ending with the LEND trainees. And parent involvement in that, and also, the statewide leadership development fees. And the focus.

WANDA FELTY:

Like you. I appreciate that. I have got less than 10 minutes and I am going to do this. So the next question is really a hard one, and it is the one that will give us the most information about what we're doing. And what were the barriers to be able to overcome, in those first years, and how?

Again, I have 10 minutes and we have to be short because I would like you all to answer the last question. So I am going to open up to whoever... Let's see... I am looking for I contact... Friend. You make eye contact, so, it is on Zoom.

FRAN GOLDFARB:

I will take it. I was welcomed by our faculty, and treated like a fellow discipline Director from the start. I think that some of that might have had to do with the fact that before we had faculty, we had training. So, our faculty, from other disciplines, who are already seeing the work of permanently and LEND programs.

But I think that one of my biggest barriers the fact that I was on the frontier. I did not have any models to refer to, in developing my program. Hyatt, and I had to learn the LEND, and then they said "

BARBARA LEVITZ:

I wanted to add to what friend was saying, by interacting with one another we had some good instructional strategies, resources, some of which we developed and identified, I know for me, I felt like I really wanted a lot more time allocated to family topics within curriculums and doing field experiences, connecting with family and the communities.

I think by having the opportunity to share some of the strategies and ideas, it was a barrier that they was able to overcome and say "OK, we can do it this way and we can provide this opportunity For" I think that is really important.

WANDA FELTY:

I'm hearing that it is really important supporting each other through those hard times, we learned through each other and persist without even approaching the barrier. Are there any other answers before I move on? OK, I will move to the last question.

This is really the closing question so I want everybody to answer this one, and I really want you to think what the answer and then think about it from your closing remarks for you as one of the OG, old guards, of the family discipline. Where would you like to see the LEND family discipline go into the future? Where have you trained? When it scores up what you wanted to be?

I will start on my screen from right to left. Jan, where would you like to see the LEND family discipline

to go?

JAN MOSS:

Would like to see it of course continue on the same track that it is going, but I would like to see... An inclusion of our family members with disabilities. I would like to see a person with disability that is recognized for their experiences and having one.

I testified in DC on family support and some of the things that I have heard from individuals with disabilities just floored me and makes me so proud of them. It made me think so differently about how the lived experience needs to be included in everything that we do.

I know that one young man said, "my parents send me to the finest place I could go to get the physical therapy that I needed." Well I don't care how good that therapy was, it did not replace being at home with his family.

WANDA FELTY:

That is powerful. I have to let you know that I will open this up for questions so really quickly, just with one sentence, where would you like to see LEND go with the family discipline. Market?

MARK SMITH:

I would like to see it continue to move beyond just LEND towards all of the AUCD training programs of which there are numerous.

I think all of us could benefit from the strengthening of the family voice and we have representatives of other programs with us today, but that would be something that I have done some work towards and would like to see continue.

WANDA FELTY:

I love that idea. Paula?

PAULA PETRY:

Perhaps a grief and stress first responder program.

WANDA FELTY:

Wow. That's powerful.

PAULA PETRY:

I think the resiliency that each one of us need in the next 20 years is something that needs to be paid attention to. So, we put together a women's summit before a huge conference similar to what you did with family discipline, and in today's it is 150 mothers with disabilities and grandmothers who have signed up.

WANDA FELTY:

Wow.

PAULA PETRY:

It is on stress and holistic practices and the blending of science.

WANDA FELTY:

I love that. Barbara?

BARBARA LEVITZ:

I would just say that I am grateful that the network is continuing to build on the history and continue and revising materials, resources, publications, to better meet the needs of how things have changed and I think that the goals have been set by this so-called next generation, I guess, they are just outstanding.

I am grateful for that and I feel very positive about the direction things are going and and congratulations to everyone, thank you for everybody who has been working together.

WANDA FELTY:

Thank you, Barb. Fran?

FRAN GOLDFARB:

I'm going to take two remarks but I'm going to do them quickly. We have been so successful in helping to grow leaders and helping to grow family as a discipline. One of the places that I want to see this spread is that family support becomes a billable service and so that not only do we grow leaders but we can adequately support and fund the work they are doing.

The second thing that I wanted to say is it just like we know from the research that's been done around least restrictive environments that not only do our kids learn better in an inclusive environment but the other kids also benefit from our kids being there. I think that is the same thing that we think of it with family support, that we not only think about what is the benefit to our trainees participating in LEND but what is the benefit to the trainees from every other discipline learning with and from family members?

WANDA FELTY:

Fran, that is so important. I love both of those ideas. We will write them down. I think for the LEND family discipline network you guys have put a market down for us, number one, to learn from but every one of these ideas from moving forward is a great benchmark for us to go towards. So, thank you all for your leadership. Were there any questions?

JACKIE CYZIA:

There is one question. It is asking how we can bring more family leader diversity, not only from different languages, but different generations into the LEND faculty?

WANDA FELTY:

Who would like to take that? Mark?

JAN MOSS:

We can do it in the same way we did recruiting and supporting family members, it would not be hard at all, I would imagine to survey the number of siblings that he would like to become involved and the number of fathers and that kind of thing stop what we have done with ourselves we can do with others and make it more diverse.

WANDA FELTY:

I agree.

MARK SMITH:

It is important mentioning that we have a diversity specialist on our LEND brand. We are trying to actively, it is not a box to check, to something, especially if you know (unknown name), she is quite passionate. This is not a question, it is something we need to do. Just talking about families and family trainees this whole idea and the enthusiasm of diversity and inclusion and equity in the LUNCH programs is something that has to happen period.

We are already a few steps down that road and we have a lot further to go but, you know, it just has to be a priority and direction that we identify. Look as options and go forward.

FRAN GOLDFARB:

I would like to say this is a peaceful lead-in for our next workshop. As I mentioned, we love to survey ourselves. (Laughs) So we actually did a diversity survey to really look at the diversity and I don't want to steal the thunder from the next presentation but I am very proud to say that when we ask "how your LEND finds diversity?" It was a broad array of items from language, gender, sexual identification, we are really on board with keeping LEND as diverse as possible.

WANDA FELTY:

I want to thank all of the panelists for coming today. Thank you so much. Your leadership has brought us to where we are today and I look forward to your leadership taking us further down the road. So, thank you so much. I am going to hand it over to Kristin, wherever she is.

KRISTIN FLOTT:

Hi Wanda! Thank you so much for the panelists for being here and Wanda and friend thank you so much for a wonderful workshop and presentation. As I said in the chat box we are standing on the shoulders of giants and I hope that we are able do you proud and think you for all of your work and I think you for being here, it is greatly appreciated.

With that being said I know we have a break coming up and so we are going to break until, for about 10 minutes, until 4:20 and then please come back for our second workshop, workshop B on diversity and inclusion in the LEND Family Discipline. Alright, see you soon. Thanks everyone!

(Break)

KRISTIN FLOTT:

Welcome back. I have 3:20 PM Central standard Time. On my clock. So we are going to go ahead and proceed to workshop B. And I would like to introduce Jonna Mulvaney and terror Marco, and they are going to present on diversity and inclusion in the LEND family discipline, reflection, and lessons learned. Thank you! Thank you for coming!

JONNA MULVANEY:

Thank you! Thank you for coming! I am a mother of two children, one who is only autism spectrum, that is really how I started this journey. And, I am also the family coordinator for the Rhode Island LEND.

TIM MARKLE:

I am happy to be here with all of you. And if Marco, I am the LEND family discipline Kwabena Boahen concert. I am coming to the role of the father of a 23-year-old, on the autism spectrum. It is great to be here today.

JONNA MULVANEY:

Can you give us a little overview of the process of how this came to be, and what I will work was?

TIM MARKLE:

Absolutely! (indiscernible) this is a really big, important topic. So we try not to enter it obviously too brightly. But I definitely entered it, and I cannot speak for everybody, with trepidation and a little uncertainty about what I'm going to find.

So we did our best to figure out and set a couple of groundwaters but what we really wanted. We wanted to find LEND graduates who were, what we would consider to be diverse backgrounds. Now, whenever I use the word diversity, it is almost exclusionary and inclusionary all the same time. So just using the language was very difficult, to try to get to what we thought we might want to know.

And so, we were very... We took our time. And we received help from the (unknown name) Centre for health equity, on UW Madison campus. With help from a graffiti. From (unknown name) down in Florida. And from fellow LEND trainees from what I would consider to be diverse background.

And all of that was just to put together a four question survey. And so, the survey was centred on what was our experience, as a trainee, considering coming from a diverse background. We then asked the LEND the actors, and training directors, as well as family discipline directors, to select trainees that they feel what part of this group that were trying to collect the information from.

We love our survey. And when we survey, we then aggregate all of this data, and so I am not sure if we're hearing all of the voices. And so we really wanted to hear different voices and everybody who normally answered surveys. Which we do not know! Maybe these are the people that always enter the service! We have no idea! So we did our best to try to really reach out to people boxes we wanted to hear, and opinions we wanted to learn from. Because I cannot tell you what it is like in different states, and having different family structures, and coming from... I for my ethnic and cultural background,

nobody else's.

And so, I cannot speak to that diversity. And so I need to know the voices, if I want to learn. That is how I am going to have to learn. So we sent out the survey, we asked the LEND to send it out, and we got about 30 responses. Part of that survey was "Would you be willing to be contacted for a follow-up?" It also includes some further questions about the gravity.

We then went through and interviewed as many people as we have. By now, we were running out of time. We interviewed a number of family members, and we were excited that so many of them were able to join us today, and share their experiences. So it was a very... It was a very learning process. And as we put together the questions and look over the responses, what struck me and it will be notified to any other panelist? Here today, that I've talked to you all already, I revealed my own unconscious biases. I had expectations. And I had a hypothesis, based on my background. Based on my part. And damn it all if I was not wrong.

And so, I really enjoy meeting these undergraduate to setback. Who helped teach me. And who open my eyes to my own biases. So I really appreciate that. So I hope that we will be open to learning from the pellet that we have here today as well.

JONNA MULVANEY:

There is so much to learn here. And I get the privilege to introduce all of our trainees. So you know, they came from everywhere and you can see, we have trainees from Wisconsin, Oklahoma, Tennessee, and Rhode Island. So we were hitting many places throughout the United States and we are really excited to have you all here.

I am going to introduce you a pixel. She is a 2019 family graduate, and she is the kinship... She is a kinship adoptive parent, with her twin sister. And, how whole story is really amazing, and I am just in our of everything that you ever thought.

How your forward, she completed (unknown name) in Tennessee in 2020. She is a family resort better test for family voices of Tennessee. And she continues to serve families who have children of you with special health care needs, chronic health issues and abilities.

And she is also the proud mother of three amazing children. We also have Angela Hornsby with us, and once she had her child, she became involved with the Down syndrome Association of Central,. After about one year and a lay member, she was then elected to the board of directors, where she served three years. She is a proud member of policymaking, and after graduating from (unknown name), life change so much. She had the opportunity to work with the Oklahoma family network, as a (unknown name) --

\*\*Audio lost\*\*

\*\*Audio restored\*\*

JONNA MULVANEY:

And then we have Chan Stroman. The University of Wisconsin, Madison. She is an Attorney in Wisconsin, next the and for students of colour and because of this abilities. And a pro bono meeting tutor. So these are all of our training that we have with us today, and we are going to start by asking them a few questions. So thank you so much.

TIM MARKLE:

Fantastic! I cannot see on my screen, whereupon you was able to join it or not. I can see, I am going to assume she is somewhere. And if not, we're probably going to hope that everything is OK. Because we are family members. That is what we do. When our car! Fellow family members do not turn up.

I am so excited to get a chance to talk to you guys again. I am still working on winning the lottery, so we can all fly together and meet in person and talk about everything that we are up to. Because you guys are just amazing! I am so excited that you are here.

But besides how amazing you are, and you can teach us so many different things, we really want to narrow in on diversity, and LEND, and the family discipline. So the three event diagrams that we think about.

So in my interviewing, of all of you all, I think (indiscernible) discipline in my LEND program. How did you respond to that? What are your thoughts? What are your experiences?

SPEAKER:

For me, not only is... As a black--Black woman, Oklahoma transplant. LEND has probably been my most diverse experience in community because it brings together the professional, the parent, the self advocate. We bring them altogether. And then when you look at the family discipline, in my case, I single-parent of colour. You have been very parent, family discipline siblings. It brings together so many different places where we all call those places community. Or culture. It gives it a chance for us to really branch out and bring so many different areas.

TIM MARKLE:

Thank you. I'm going to try to answer-- not answer after everybody. Rachel, come on in.

SPEAKER:

Thank you for including me. I also wanted to, first say thank you to all the pioneers of LEND because I believe your groundwork is what made me feel so welcome and included in my LEND program. I was seen as an expert in my field, my field being my family.

I really thank you all for that. Just to add to what Angela said I think here in Rhode Island, for me, LEND was the most diverse opportunity to be in the community that I have been in. I'm 43 years old and I have grown up in Rhode Island. I have not ever felt so included, welcomed and wanted in something before I attended in my LEND program.

Now, having said that, I would love to see this term "Family" Brought in to include more families that

are nontraditional. I am an adoptive mother of five, and I would like to see more families that are not traditional in that sense, to be included in that family term.

JONNA MULVANEY:

Can you think of any other discipline, other than the adoptive, what else could we include that would make it look better?

SPEAKER:

I think I must start raising children with my sister. It's not a goal we set out in life to do. It's very unique, and I often, because I support families who have just had children placed in our home I do see a lot of older siblings raising their younger siblings.

I think broadening that to include those families as well. I just attended my nieces same-sex marriage, so including the families of same-sex families.

Any traditional family you can think of I think should be included in that term of family.

JONNA MULVANEY:

Thank you, Rachel.

SPEAKER:

I was going to comment kind of maybe flipping the topic around a bit. The diversity of the family discipline in comparison to other disciplines I think raises interesting questions about what are the barriers to diversity, Equity and Inclusion and other disciplines?

I think a pretty easy data review would simply be the grad programs. What is the diversity in the grad programs? What are the barriers to getting sufficient diversity, sufficient candidates into the pipeline so they end up in graduate programs, and have the opportunity to participate in the graduate school based disciplines.

And I say that from my perspective on the family discipline and what I felt as a family training-- trainee was that the other disciplines had a lot to learn from what trainees and the family discipline brought to the table. And I think that is still, well maybe it's just me, but I think that's a little counterintuitive.

I think what I'd like to do, you know, whenever anyone asks me about my experience in the family discipline, or what I think the family discipline should be generically asked someone in society would like to see society benefit from the LEND program is that family discipline has a lot to offer and that should be recognized, and once it is better recognized all the other disciplines, and LEND as a whole will have a lot to benefit from it.

SPEAKER:

I don't know if this is the space, because I family discipline, sometimes I don't know all the rules, but I heard something very interesting, Chan about what it says about the makeup that helps disciplines.

I heard someone earlier say that there is a role for diversity and inclusion in some of our LEND programs. What I would love to see is in states where we have HBCUs that we actively recruit maybe some participants from grad programs where we have students of color where we can get them to participate in the LEND program as interns.

TIM MARKLE:

Angela, for those of us who may not be as familiar can you please explain, you know I mean?

SPEAKER:

HBCUs stands for historically black colleges and universities where they are predominantly, of course accepting of all, but predominantly black students.

SPEAKER:

I think when I spoke to Tim one-on-one when we first met and I think it kind of piggybacks with what Mark had said earlier about diversity and inclusion is it is really not a question, it's something that has to be deliberately done, and I think I had set it might LEND program with Jonna, probably several times, it's something that needs to be delivered. There's no more time to just that, "If people want to get involved they will come get involved."

It needs to be deliberate. If we want different people from different backgrounds with different experience we should deliberately go out and try to recruit them.

TIM MARKLE:

Rachel, besides recruiting are there things that the LEND programs can do to recruit and support a more diverse family trainee set?

SPEAKER:

I'm sorry, if you say that again?

TIM MARKLE:

Number one, thank you. In addition to what you just said is there anything specific you can think up that LEND programs can do to support their family trainees or to work on recruiting more diverse family trainees?

SPEAKER:

I believe that not only Angela gave the example of the historically black colleges and universities, but here in Rhode Island we have a lot of organizations that support families. I a nontraditional family in that I and adopted family. We have a lot of organizations that support those families that LEND could reach out to.

I don't feel like a LEND family participant has to be somebody who is doing well within their family. Like, working with their child. Maybe it is someone who you see is working with a child with special needs, and could use the support of their family members that are doing well with their child.

But, support in that sense. Also in the schools, I know my children, I have five, two of them are on the autism spectrum. They are always meeting the special education team at their schools. If LEND is involved in that way and recruiting parents through that channel.

And just supporting if a LEND family graduate or faculty what have you can go and do talks at a school to help support because they learn different ways-- learned different ways for the family to feel empowered and then go to the healthcare providers I think that is huge because that's the one thing I got from LEND, is I do walk into meetings with my head high and I know I an expert in my field.

That came through LEND.

JONNA MULVANEY:

That's amazing. Angela, you had a question?

SPEAKER:

I want to chime in about how LEND can be more diverse. I think visibility and going into those other spaces because, I'm just going to be frank because this is the topic, OK? I just going to use comfortable language. I have not going to go to switch purposely.-- Code switch purposely

White America what you will consider general spaces we consider white spaces. It is not ours. It is not a joint space. LEND has to become visible in our spaces, do you understand what I'm saying?

I also wanted to share the importance of the LEND family mentor where the interns get a chance to partner with family members. It is a very interesting perspective, I sure, to go to your IEP meeting in a different ZIP Code with different standards and understandings and desires to deliver to our children.

When I amend family member-- LEND family member, I took about six members to my IEP because all three LEND we discussed what a good IEP looks like and what is rightfully ours. And then you come to my IEP in urban Oklahoma City bearing they are less cooperative I think it gives a fresh perspective on what we felt, but don't get a chance to see in action.

I think the diversity does not just have to be in the interests, not just in the faculty, it also has to be in the mentor as well as the experiences that we have to complete to complete LEND, we have to make that look more diverse as well.

JONNA MULVANEY:

I don't want to put words in your mouth, but I think what we are summarizing is that we should be representing the communities in which we are supporting, correct? And sometimes that doesn't always happen. It is difficult. Thank you, Angela.

TIM MARKLE:

Chan, do you have any thoughts-- thoughts for room on growth other than what Angela and Rachel have shared?

SPEAKER:

I guess I would suggest stepping back. What is the purpose of recruitment? There is a big difference between saying, we want to recruit more, however you want to define diverse, so that we can say this year we had a more diverse class. That cannot be the driving purpose.

I think, certainly I remember from my LEND year, and I know this must be hardwired in every single LEND program. You got a very standard set of goals and objectives and principles, right? And if you take those seriously, and if you go back to the origin of why LEND exists recruitment has to serve that purpose.

That is suggestion number one. The second suggestion I would have is, what is it going to do for the person you are trying to include? They are not there to serve LEND. LEND should be there to be able to say, "Here's an opportunity that we hope can be constructive and productive and give you something that is helpful for you."

Because, let's face it, everybody who is in LEND through the traditional grant program pipeline to some extent it is fairly resume building, career oriented. There is usually a pretty clear, obvious reason why someone in a grad program would apply to LEND. ... And not to be mercenary about it but looking at recruiting for diversity in terms of what this could do for the program as opposed to what can the student for the person we are trying to recruit, is something that can get very easily overlooked.

JONNA MULVANEY:

This is true and that's unfortunate that we found so many of these services as well.

RACHEL BRIGGS:

I just wanted to point out diversity and inclusion and in my opinion it being two separate things. And I think someone had put it in the chat as well. To me, diversity is having a representative of different people in the organization, but inclusion is the ensuring that everyone has an equal opportunity to contribute and feel influenced. After LEND, I'm LEND but afterwards, and then being used to contribute to LEND in anyway? Or did I just that word that I know I don't like in MI just the quota? Was I able to contribute and after LEND and I think I brought this up before, in my LEND book. One of the graduate family participation and then they become a mentor in the next LEND. I just think this is an important part to take into consideration.

ANGELA HORNSBY:

I was going to say I completely agree. When we receive the questions, prior to, one thing that I wrote down because I did not want to forget thy unlucky enough to say that my experience, this has happened for me. Things important that when you have a minority or a person of colour who is a LEND mentor, or training, they have been chosen to be a trainee because of certain experience, correct? I think to find space for them to present the next year, about their lived experience, is an awesome chance to keep that diversity ball rolling. And then we all know that it's all about community and you know, but these opportunities for leadership on portraits and print chances, I think someone said testify in DC, we know those opportunities come from Québec remember, think outside the box. Don't just pick that same person. You know, and I think also we fail families because we choose seasoned parents. I think when I talk LEND my son might have been six and he was probably, I had

with the youngest children of my peers who had done it before. I think that if we grant that LEND in turn, earlier with their family, it will touch more lives and attach more people.

JONNA MULVANEY:

That's absolutely true. I think everything you will say is exactly what we are trying to hit on and a lot of the information that we were trying to bring forward so I think you so much for that. Tim I know you have a couple more questions right?

TIM MARKLE:

Absolutely. Just to the three of them I could just go on and on the personal interviews as well. I don't really want any of them to but so you guys have been now through this, and I do want to say that I don't know if it was one of you three but other people that I interviewed and also in the comments and the surveys also mentioned the fact that how important it is to have panelists and speakers and leaders of the diverse backgrounds as well. The full sense of being able to see myself in another person and that, I think we are moving in that direction, I hope. But that 70 mentioned that was really important to them as well. They could be in LEND and a nose like them on a panel. Or presenting one of the topics.

ANGELA HORNSBY:

Because unfortunately, for me and my experience as a family in turn, it wouldn't have mattered what colour. I was already a minority because I was not a professional in that way. Like literally, I do not know how to use Google Docs my starter. So I'm older, I'm a person of colour, you know haven't been in school and a zillion years, we already have so many ways where we are not alike in LEND that it would've been helpful to see another person, similar to being in some way in the class.

JONNA MULVANEY:

That is something that we did hear loud and clear throughout some of the other questions and surveys that we have done through that. Tim, I don't want to stifle this, we do have a couple of questions you do one more question with the panel that we will open it up.

TIM MARKLE:

Absolutely want to open it up have you guys, who are listening, also like this information these fantastic panelists have done. The last question is what words and wisdom, you have been on the road, what words of wisdom you have for future family discipline trainees?

ANGELA HORNSBY:

I would say, take the opportunity. It's an opportunity to learn about more than just your particular journey. Whatever your child or loved ones disability may be. But then, once you are down, don't stop. Keep those connections, when you talk to other parents tell them about your experience with LEND. We can't... Especially us, let's be honest. We can't take this information and keep it to ourselves. It is our charge to take this information into those same places that I was speaking of earlier. We have to commit to be the messenger, if we have had the opportunity to receive the information.

JONNA MULVANEY:

So true. There is some responsibility on the LEND family to have that responsibility. It's not all on you. It's on us as well.

TIM MARKLE:

Rachel or Chan?

RACHEL BRIGGS:

I was a to a family member that is going to be involved with LEND, don't let the big words distract you or discourage you. That's why there's dictionaries and people you can ask that me and what is the acronym? You have a title. And your title is you are expert in your field and your field is your family. That is what I would tell anyone being involved with LEND. And also to piggyback on what Angela said, once you are done, we are like Harry Truman's and we need to go back and give the information and just keep going back and forth until we are all saved from whatever, we are in bondage of. So that's how I consider myself.

CHAN STROMAN:

Thank you Rachel. That's how I feel about non-LEND things unfolded thank you so much for that Rachel. The advice I would give is, and this may vary from program to program, but my sense is that LEND as a whole has not necessarily come to grips with the huge intentional-- potential of what the family discipline family discipline treaties can bring to the program. In my advice from day one would be go in there, trainee, and act like the expert because you are the expert. It is the expert on your discipline, you know, the expert on was the program should be like, if it isn't. To ensure the most integrated, the most inclusive, the most diverse and the most productive use of your talents and knowledge. And again, I would encourage... There's a lot that is built into an academic setting that is intended to, almost by design, even if it is not thought out that way. It intended to be intimidated. That's why you have jargon, excitement academic papers actually, if you read them, are hard to read because they are poorly written. Not because they are hiding some wisdom that only certain people can have access to.

So I would say, go in as a training, day one, I'm the expert I'm here to learn as well. But I'm going to keep my eyes open and I'm not going to be shot-- shy about the things that need to be better and I have the ideas how to make them better, I would open my mouth and make it clear, what those suggestions might be and who should listen to them and to try to have some accountability for making those ideas go somewhere.

TIM MARKLE:

Thank you guys so much. Let's go hit and takes a questions from the participants, the attendees right now. John had he been keeping track of who is holding their handout?

JONNA MULVANEY:

Stephanie Coleman from Kansas, she was our first question.

SPEAKER:

this has been fantastic this thing to all of you but one of the big things that Angela had mentioned, and

will bypass us in life now, is to create efficacy across Kansas, the matter where you live, matter what colour you are, and you mentioned... And I was the same way, I'm not a spring chicken as a human as a LEND trainee as well. I had an oversight. How do we recruit younger, people with younger children, that can afford to participate in LEND because you know, we are not giving a huge salary right? That is really my question. I want to do that, I want to get them younger, so how do we do that? Thoughts?

ANGELA HORNSBY:

Actually means...

SPEAKER:

We do here in Kansas.

ANGELA HORNSBY:

Because I'm working families were usually have and raising a child with a disability, stops everything. So despite the is an incentive actually. It's one day a week, it's only for a few hours, get the information and, you get a little stipend. I think you would be surprised, I get, demographically, that stipend was a big deal.

SPEAKER:

I understand, as in, I completely relate but I have been told, over and over again that they just can't afford it and Kansas we have our classes in the engine may be more than two so

ANGELA HORNSBY:

Offering childcare excitement when it comes to the family discipline, can I bring my baby with me? I took Malachi a lot of places with me as I began this journey

SPEAKER:

And let's give the other trainees and some hands on experience right? I love that idea.

JONNA MULVANEY:

70 what was the question is that your question actually came up and throughout all of our surveys on more than one person saying it's not about the diversity piece so much as the family discipline itself. And I think that where the same because we got to go, these surveys were certainly it was really actually shocking to ask because it was necessary... Necessarily, it wasn't about family discipline as a whole and not as trying to make it more diverse. So I just thought that would be really important to share because that was really a highlight for us.

TIM MARKLE:

And that was something that a number of different trainees shared. When I think about the acceptance and welcoming attitude that there was more, or just as much barriers by being a family member in a room of professionals, then whatever cultural or ethnic background there might have been.

That we are still struggling to bring families up to level that they deserve to be at. And I think, LaTysa, did you have a question?

SPEAKER:

Thank you very much for acknowledging my hand. I want to say thank you to the panelists. Thank you to Angela, Rachel and Chan for being here and lifting up this conversation. I appreciate your contributions. Somebody thinks came up from the very first question when you asked, what you think it is that the LEND program is so diverse?

My mind went immediately to differences are naturally occurring phenomenon in nature. And so, disability is a naturally occurring phenomenon. It doesn't discriminate.

Then when we look at our programs there starts to be a difference in representation because now we enter into a human made system, right? Of selection and identification.

I wanted to say, we have so many things in common from the family support discipline, but when it comes to the intersectionality of identities, when it comes to being a woman of color or parents of color of the child with a disability I say there are options that people have. Often, Black women have the option of doing what we need to do and what we have to do. While women who have other ethnicities have other options.

They have what they want to do, what they should do, what they could do. We have these two options most often. What we have to do and what we need to do. Those are two competing priorities for us. There's not even really hierarchy.

I wanted to look at some of the other things that are differences. Like how does ethnicity impact the social determinants of health? We all know that they do. And so when we have these disparities that exist in the way that services are delivered, the amount of services that get delivered, the amount of money spent on families based on ethnicity we have a whole lot of things to consider here.

And then somebody asked the question about, I think it was you, Chan other that you get people in grad programs participating. Doing what you have to do and what you need to do, right?

And so, for me, thank you Fran for all the encouragement. I was one of her trainings and she was on me. I think one of what's-- some of what's missing in the learning curve with other people in land is there's also this internalized oppression, internalized feelings of inferiority that come with us when we come into these types of settings.

And then not being able to do everything that you want to do. When I came into LEND I was in school but I just want to tell Fran, I finished a law degree, a social sciences, Haverhill sciences degree,-- behavioural sciences degree. Black studies degree, and I'm finishing the last two classes for psychology degree.

These are all minor degrees because I did not allow what I could not do to prevent me what I can do. And so we need to look closely at his terminology. Many ways of knowing and ways of expressing or articulating what expertise looks like.

It took a long time to get those degrees and to be a longtime late fellow. How do we articulate that, Marketplace, and we look at people like myself who have a broad amount of experience. Not just lived experience but academic experience. Just because I could not go into a graduate program some to speak how can we open the door? I can remove some barriers of the light say, you know what? Let's look at her academic progress and let's articulate this and say, "This associates again to doctoral program." If you want us there you're going to have to do more than once is there. You have to look at things a bit differently to get us there.

TIM MARKLE:

We are running right against the break, and as I fully intended I didn't want to talk hardly at all. You all are phenomenal. Thank you.

JONNA MULVANEY:

Maybe we could take this to the virtual happy hour at the end, most of this conversation. The chat.

TIM MARKLE:

There some fantastic stuff in the chat. Angela, Rachel, Chan thank you for sharing parts of your life with us and I continue to learn, which is one of my favourite things to do.

Thank you for feeding me. I hope you have a great rest of the afternoon.

JONNA MULVANEY:

Thank you so much.

SPEAKER:

They could to our panelists also for being here today. I have a lot to think about and it is very powerful. I hope we are able to go back and listen to this again. Because we are recording. I in all of your wise words.-- In all of your wise words.

We will take a 10 minute break and come back at 5:15 PM for our virtual poster session which will be moderated by Stephanie Coleman. See you in about eight minutes. Thank you.

(BREAK)

SPEAKER:

Thanks Kristin. I am Stephanie Coleman, and family educator at the University of Kansas medical Centre and the family discipline mentor at Kansas LEND. First of all I am a family member because of six-year-old son on the spectrum. And I was a family trainee in 2015, 16, and then started in this position 2018. So almost 4 years now. I'm really excited about that.

One of the things that I learned, in my position now, is that LEND across the country are not overstated. They all do things differently3-- they are not focusing. Even the family areas they do things

differently. So I wanted to have an opportunity for us to create space for this conference so that we can share our uniqueness as everybody else. And hopefully, sparks and ideas for the new LEND coming on for-- board. Some of the younger family LEND that continue to grow their discipline and their family discipline. So with that said, we have four posters that are going to be shared today. We will each present for five minutes and then we are going to leave time for questions at the end. So feel free to put your questions in the box, or wait until the end but all of us will be available for questions at the end.

They also want to make note, as well, all these posters are contact information so if you're questions do not answer, please do not ever hesitate to reach out to us and ask us about anything that you have questions about. So that's it. Next slide please.

Thank you. And this is the Kansas LEND poster. I'm not going to read it because you can go back and look at yourself. I am promising that the Kansas LEND program is one of the original members of the University affiliated program. Do not ask me what that network is all but because I was not even back then. I mean, on earth, back then more or less. LEND we make continuous funding for nearly 60 years. So I'm pretty proud that opportunity to be able to continue on what so many before me started in Kansas.

Our family discipline, the First Family training was in 2008 they have been parents and siblings and when I say parents, we've had adoptive parents, and we've had homes.-- Moms. Unfortunately we have not had any debts. It is something that I hope we can change at some point. We will just have to wait and see.

I also want to take diversity, we all know COVID-19 was a bad thing but in a way for us LEED it was kind of a good thing because it has opened up our area. I am in Kansas City Kansas where if you don't and geography, Kansas City is very much the northeast corner of Kansas. Real estate line Missouri. So I can't get to other areas and have them just drive in to be able to participate, as a family member.

But I hope that we can get beyond the broad definition and Rae-Leigh Stark including rural and frontier families as well. Mostly because the things that I think about his being in the Metro area, as we have all kinds of opportunities supports and resources and our hands. But they don't have that in the rural and frontier areas. So how can we, as the LEND program, growth is family members to be able to possibly providing those resources and services.

The one program modifications that we started this year, is that we now have a second year and also to talk about our key MCH. Elizabeth reciprocal -- there is a mentorship program, I hope you will be attending but if not it will be recorded. Our trainees are paired with families across the state and they need them to flee, virtually, and anything they think about and learn are keeping their families in mind and talking to the families of the different ideas.

Another program I started was an education series. Once a month, to provide a session on topics of interest for families, and then we Facebook like it so anywhere in the state get the information. We

also archive it on YouTube so they can go back get that information later. Again, I told you we are the Metro area where families have the opportunities to have workshops all the time those workshops are not always put on for our rural and frontier families in Kansas. So I really wanted to give them the opportunity to study the same information that we all needed, some of that or those topics include special education, advocacy, self-care for themselves, and, we just recently bought an awesome evaluation looks like because we get a lot of questions about autism evaluation. So now we can go and say here, take a look at this.

We started into your program just this year, we have, for the first time ever, we have second-tier trainees-- second year. When I was a trainee, it went like that. And I wasn't sure. I was like now what? And so, a couple of the things the last panel was talking about, is how we continue to develop them, the trainees, to be able to go out and change the world? And I feel like second-year program, they're going to continue to develop certain competencies they chose and they can go out and learn from some of our community partners, through shadowing and internship opportunities.

One of the things, also, and Rachel mentioned it, in the last session, as mentoring others. Our second year trainees, mentor our first year trainees. Which is kind of great because it helps me in that area as well. So gives them an opportunity, not only to hold their leadership skills, but their mentorship skills as well.

One of the other things I learned, were different, is we don't have an educational apartment for families. We would like to see efficacy experience, and that can be just advocating for their child at school, or the healthcare area.

I have one minute so, we definitely have opportunities for growth and the diversity of family trainees, as I mentioned earlier, I would like to see younger families, once the rural and frontier, definitely. From all races and sexualities, all of these areas.

And I also see us do a better job of assisting family treaties in life after that. So I will stop here like informational seconds cut off the bottom of my screen, but anyways, I will stop here and move on to the next person which I think is New Hampshire... Yes. And it is Julie.... I'm not seeing your name on the poster so I apologize Julie....

Can somebody go back one

**SPEAKER:**

Threesome lemonade is not of the top posters because we actually have on the slides! one. Family faculty team this year, so the premise.... So the New Hampshire mainland is back this year to be celebrating its 30th anniversary, Julie Smith and I have been a family faculty member since 2008. I am presenting the poster on behalf of our faculty, our family faculty team citizens Zimmer said. Our program was established in 2002 2011 joint program with the University of Maine. At that time it was a videoconferencing classroom because DiSC between the two campuses which allows the main trainees to participate remotely.

After our experience with COVID-19 last year, now why..... I have here in the middle you have reinforcing joint sessions which allows members and trainees, and students and professionals to all get to know one another, and we kicked off two days in New Hampshire, we will meet again midyear to start our policy module and then wrap up the end-of-the-year poster session.

This model has been very well received by the family discipline methods as well as grad students and professionals. Because in this release enables easier access for all this he is. Especially in rural areas are very important.

It is very important on average, lower courts are so bright that 40. ... Our first family member is eight the title and I also joined the program and eight... In 2008.

Our first official family discipline training in 2011. We have always included family members to be part of our graduate-level programming, and the strongest factor in their success, we feel, family faculty mentoring each trainee.

So the strength of our program really lies in our futures. So we have individualized opportunities for all of our programs trainees and their family perspectives, family perspectives integrated into every learning opportunity across our curriculum. Hundred 50 clinical leadership hours that are placed on sites and projects new Mac They are also in our community areas and agencies to share and effect... Share their perspective and affect policy and practice among states.

They also have the opportunity it's important to develop their own unique leadership plans, and they set their own goals in their own personal and professional goals, and also leadership and advocacy goals, that may encompass their specific interest in disability and how it affects their families.

Our families are really well integrated into our program because we have a team-based learning program within our program. So, each family member is placed on a team so this year we have three teams of six and their experiences are integrated in all aspects of the topics we are teaching and learning in seminar.

It's within these teams they have a really nice opportunity to build trust and relationships with the grad students and the professionals teaching them and then in turn learning from them as well.

We also have a lot of case-based learning applications. We put together cases and all trainees prepare and often the family component is one of the strongest parts of each case and families have a way to share their perspective with their real-life experiences and feel solidly part of the cohort.

Opportunities works. Right now, this year we are increasing our universal design and accessibility of raw materials for all trainees. We are really working hard to increase our cultural and ethnic diversity of our family trainees in the rural straight, it's very difficult sometimes to find diversity in our small towns.

We are also looking forward to strengthening our family discipline alumni network.

Having keep all of our family discipline members connected? Thank you.

STEPHANIE COLEMAN:

Thank you, Julie. Next up is Linda Rousseau from Alabama. Linda?

SPEAKER:

Hi, everybody. My name is Linda Russo, and welcome to this part of the afternoon. So, I work in Birmingham Alabama, which is midstate. I guess it is the third largest, third or fourth largest city in the state. Pretty urban. I can read-- I commute an hour so I'm a little more moral.

I started at the pediatric pulmonary Centre. I started there is a trainee and that I kind of or filter into LEND as a family training. Then took over as the family faculty. Our program, has been the LEND program for over 40 years. It's based in the (unknown term) clinic which is a unique setting for us to have our trainees learn a lot about a big autism focus. We also have a dental clinic and a really large ideology, nutrition program also.

We have sparks pediatric clinic which we get to rotate through. That's kind of where our trainees learn and get to see families and other experiences.

So, I said, the First Family faculty was in 2011. I started 2015. I was the First Family training and I've had several trainees since I've been there and sell full-- several self advocacy trainings. Really need to bring them on board also.

We recruit our trainees through networks that we build up in our title V partners. Family voices, I think every state is one of those. They are a great resource.

Our trainees go through the curriculum with the same requirements as the other trainees. We do modify it some so usually there time requirement is not as great as long-term. Other trainees are there five days a week.

We have the one to two year option at most of my family trainees enjoy it so much they just want to be there, so they stay the extra year. It has kind of turned into a two-year program for growth and development. There are so many opportunities for them to be a part of and to grow and talk with other trainees. We really have enjoyed the two-year option.

The qualifications that we have our religious for education purposes, just a high school diploma. Of course, other postgraduate work does help when you are engaging with the other trainees but is not a requirement.

It's a family member, primary caregiver or self advocate. Our modifications we have fringe training and individualized training for everyone when they come in, and suffer our family trainees we see what they need so that they will be successful.

And kind of fell at him from the faculty from the University Centre, or other peers that we have.

We are also trying to develop this year a peer mentor program for self advocate trainees, parent with a second gear. In psychology. So they have a sense of feeling that they already belong and they know where to go and are not just thrown in there to all the other disciplines when they go in so they have a friend to go in. Next semester we are trying to switch them to another discipline that they would like to view, and have another mentor for them.

Orientation. We view intelligent lives. I don't know if everybody has seen that movie with different people with disabilities, and then we have a debrief afterwards. We found that's a great way to encourage inclusion and get everybody talking about it. Usually people have disability touch their life in some way.

Another experience that we do I've kinda found that are to find some families that want to stay with us and have our trainees come into the home and do that, so we have partnered with some local agencies and the trainees will spend a day with them and see what their programs are doing and kind of focus on one or two of the self advocates or family members and get more in-depth conversation with them, and that's been very helpful.

We have core lecturers in our trainees, they present to the rest of the class and talk about their experiences. It helps them develop their communication skills.

We have a new director this year and a new training coordinator so we are excited and very supportive of the family program and also excited to be expanding our family faculty. We have a new member on the call, when brown. Give her a shout out.

Great to see her jumping in and getting engaged with everything.

This past year I feel like everybody else we are doing everything remote, but moving back into what we did kind of pre-pandemic and hopefully continuing the hybrid model which is more accessible and flexible for family members. I think that's about all that I have.

STEPHANIE COLEMAN:

We appreciate that overview of Alabama LEND next up is Indiana LEND.

SPEAKER:

Hello, everybody. Christy James with Indiana LEND. Family discipline coordinator, I also play other roles but that is my primary one.

Our program has been around since 1970 so we are one of the earlier programs as well. I have had family faculty since 2009, but our first family training was in 2005.

One of the key program points is that we have full-time faculty, and that has made a big difference in our ability to mentor the family trainees and integrate family with our training program.

We have the family faculty person. We have been lucky since 2009 the family faculty has either been

our training Director,

Or an associate training Director so that really helped keep that really tight integration and then every didactic session we have, so our whole cohort of long-term trainees will meet every other Friday.

During those didactic sessions we always have the story hour, we call it, and it's either a family or a self advocates perspective on what ever topic we have been training on that day.

And then our family trainees are fully involved with the cohort. They attend all the didactics and work projects just like the grad students who are in the more professional fields. They really do a great job of sharing new perspectives and have helped our other trainees learn and grow so much that it's been invaluable to them, and it's also been wonderful to have them come back.

As I said, that story our a lot of our previous trainees would want to come back and do that one hour talk later groups, cohorts of students coming through. It has been really nice for us.

I will let you read this slide it yourself but we do have a hybrid format that has really helped a lot for getting that more diverse cohort of family trainees. We always, for our in person didactic book, we always alter a life stream of it and I'm according so they can choose which of the three options works best for them. That's about it.

We have lots of great ideas within our LEND program for growing our family. Like most of us, resources and money is our biggest barrier at the moment.

That's all I have. Thanks.

STEPHANIE COLEMAN:

Thanks, Christy. It was great to hear, and I hope you heard something that sparked an interest out of one of the four LEND that were shared today. Are there any questions?

Other then, how to find more money? Because I think we would love to know that answer. (Unknown Name)?

SPEAKER:

Curious that if in some of the LEND program representatives who are right now on this LEND community if they have allowed parents concurrently to be able to attend some of the didactics or seminar sessions for them to learn? Because I thinking and perhaps looking into in terms of creating my own poster for next year, perhaps inviting a community of parents where they are attending an Academy leadership for parents. It's just an idea that popped in my head. What do you think?

STEPHANIE COLEMAN:

All of our family trainees at Kansas are completely integrated and do everything that the rest of the cohort does. So, yes didactics are absolutely involved in the same didactic.

SPEAKER:

My question was related to parents who are not in the LEND program. A different academy of parents whom I was thinking I could perhaps determine if there's... There could be a research outcome there. Something to learn about the parents who are burning with me.-- Learning with me. Me being one of the long-term trainees in appearance from this academy, but something I could probably bring up to my mentor, she might be listening, but it's just an idea that popped up. Thank you.

STEPHANIE COLEMAN:

Thank you. I do have some ideas for some short-term trainings as well as family trainees. Christie and Julie I saw you turn your cameras on. Do you have an answer for that?

SPEAKER:

We do a lot of community trainings with family members and some of them are led by our LEND family trainees and then other trainees are faculty. That's a great way for us to integrate them with our program.

STEPHANIE COLEMAN:

Recruit them in for the long term. Julie, were you going to add anything?

JULIE SMITH:

I think my answer was similar. Our trainees are fully integrated into our program. I would add that in the state of New Hampshire there is an advocate series of Art Institute on disability. It's a full family of self advocates. Attend session program which has lots of opportunities for families within the state. That doesn't involve the didactic sessions and the intensity of kind of the professional path that we offer at LEND. Quick question for Linda you have altering storage intelligent-- to have all trainees watch intelligent lives?

SPEAKER:

Yes we do for two years if not three.

SPEAKER:

Next Rachel had a question.

SPEAKER:

Hi. Thank you. This is amazing. I am a brand, the San Diego LEND that just in July. Yes, thank you. It has been a very exciting time to get all of this started. I'm faculty discipline lead for our new land back so I guess I just wanted to ask panel, and know how long you'll be doing this, there's no way I can put together all the things that you all have done so quickly, but where to start? What is the most important thing, and we also are building, we like to say we are building this claim as the flying UNESCO acumen and that you thinking July, and I'm sure it has been a world view when you first started just left asked the panel for thoughts and specific to where you are and geographically but I thought it would be nice to pick your wise brains.

SPEAKER:

My quick answer is going to be the mentorship, having other families to meet with your trainees so they get that hands-on experience. It lands that lived experience right away. That would be my first thought.

SPEAKER:

To clarify, we have to, actually one of them is on this, we have two family long-term trainees who are starting with us so there will be family members that are there treaties doing long-term activities they will be the core group of nine long-term trainees, I don't that's what you are referring to.

SPEAKER:

Specifically, I'm talking to Kansas LEND families tomorrow I will be talking more about the mentoring program. To me, I think it's extremely beneficial, not just for the family trainees but for everybody else. We do have our families participate as well because I always say if your child has autism find someone who has Down syndrome and go complexities so we all are about something different. So I can hope you can join tomorrow. Julie, you have your Mike off.

SPEAKER:

I think there's some, quickly, some advantages we've seen. We have a lot of case-based activities where the core faculty, on the clinic faculty, create a case. His family story about a child with a disability is a challenge, and how we problem solve this and these are really great opportunities for families to present their family stories and then have an interdisciplinary discussion around how to find resources within the state of the communities. It only empowers families because they can present their old stories it cases, even if it is not their story, they are able to contribute as cases resolve and discuss. It is very rich.

SPEAKER:

Thank you Julie. Linda? Do you have any thoughts or Christie? I Christie said the LFDN network. It would be a great one. Linda did you have something?

SPEAKER:

As far as networking, I think the family voices and their state, they are great people and there's great organizations and a great reach. There's a lot of resources.

SPEAKER:

The question was if you could only do one or two things first, what would you do first?

SPEAKER:

Well I guess I was still say that because you need a support group around you and people that have been doing it for a while and will help you to show you some areas to go to and we have had two new PCs this year in California and they are trying to get family program up and running as well. So I kind of told that the same thing. There are already people in your state so just rejected the follower they are going. See what they are up to.

SPEAKER:

Alright, well thank you for the questions, we are just a little over so we are going to end of this session and move on to closing remarks.

JACKIE CZYZIA:

This is just a reminder to please complete the evaluation. If you are not attending tomorrow, and again, workshop recordings, resources and slides will be available within one week of today's meeting. They key.-- Thank you. Next slide.

SPEAKER:

So I'm going to wind some things up with some closing remarks I just have to say, I am just feeling so jazzed and so energized and I hope you are all feeling the same way. So I want to thank you all for joining us today. We were calling it a summit but I'm changing that to a celebration, family and LEND and related programs. Tomorrow we are going to continue even more and it includes a LEND family graduate leadership panel, a workshop on family mentoring, as Stephanie was alluding to, and a workshop on life after LEND or as we titled, my LEND family trainee membership, taught me a lot but now let's? I will also share more of our LEND programs highlighting the features of the different programs.

I want to remind you, all of you, that you are welcome to participate in the LFDN if you don't already, and the easiest way to get involved is to get involved. There's no entrance fee, there's no entrance exam, and we only (indiscernible). There are lots of opportunities and despairing to do.-- Very easy to do." Yet, but wait there's more. Please stick around for our full happy hour that starting in just a few minutes. We are going to happen tomorrow as well. Today's happy hour is just LFDN members or for any faculty, but honestly, we don't check rituals at the door so all are local. Tomorrow's officially is for everyone. Please bring a virtual or a literal drink if you would like, and take this opportunity to mingle, and to know each other, and help to launch the LFDN summit 2 the sequel. Or in the lairds of Hamilton, being in the room where it happened. This only happens if you are there to make it so.

So on to our happy hour.

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