

LEND Family Discipline Network's Fabric not Fringe Webinar Series Part 2: Family Members as Faculty, Staff, Presenters, and Panelists LEND

EMMA FOX:

Welcome folks and thank you for joining us. You are in the right place. If you came to view Part two of Fabric Not Fringe Webinar Series and today we'll talk about Family Members as Faculty and Staff and presenters and panelists and we will wait just a few moments as people continue trickling into the zoom room.

While we wait I can introduce myself and my name is Emma Fox pronouns are she/they a white woman with clear glasses, gold nose ring and dark long brown hair, which is new for me because I used to have lighter here. I'm a program specialist here at AUCD and support a lot of self advocacy and family projects and I'm very happy to be here with all of you today and thank you for joining us.

What you all should be seen as the first slide with the name of our presentation Part 2: Family Members as Faculty, Staff, Presenters, and Panelists and can I get some head nods that everyone can see all right? Awesome. Before we begin I'm going to address a full -- view logistical details and I will provide a brief introduction of the webinar series and this webinar series is based on the white paper and if you were at our first webinar you got a little intro already so this will be a nice refresher and following each speakers presentation there will be time for questions and we will have about five minutes for question time, and because the number of participants or audio -- your audio will be muted. You can paste questions via the chat box or raise your hand visually or raise your hand in the participant box and you may send a check to the whole audience or to the presenters only and let us know if you need assistance and closed captioning should be available by selecting the closed captioning button on the bottom right corner and please send us a personal check if you are having trouble accessing that feature. Entire webinar will be recorded and available on the event page one week from now and our previous webinar Part one is already archived so hopefully, you can view it if you haven't already and there will be a short evaluation survey at the close of the webinar and we invite you to provide feedback and suggestions on topics you would like to hear about from us.

Here is a visual of our agenda and we will hop right into the introduction and they'll go into family members, faculty is that adequate Q&A portion and family members is presenters and panelists by Dori Ortman and another Q&A portion. We are going to start with a quick poll to see what disciplines are here with us today. I'm going to try to launch this and hope it goes well. See a lot of LEND folks here today. Some UCEDD and some others. Is wonderful to see such a diverse representation but now we're going to welcome our experts in Family Support who will be presenting to us, and first we have Fran Goldfarb the Family Support is one director for California LEND as well as director of Community Education at Children's Hospital Los Angeles, and welcome friend. We also have Dori Ortman who is a family faculty for Lend Pittsburgh at University of Pittsburgh, so welcome Dori and to

everyone. We will jump into outward introduction with Fran.

FRAN GOLDFARB:

Emma gave you a little bit of who I am but I also wanted to share I am the share of the LEND Family Discipline Network a group that put together the Fabric Not Fringe white paper and I will provide a very short introduction and overview and you can think of me as the opening act.

Next slide, please. The webinar series is based on the fabric Not Fringe White Paper developed by the discipline network and can be accessed on the AUCD website or through the link that you see on the slides. Fabric not Fringe looks at all the ways family have been involved in LENDs and family releases at the core of all LEND values and programs an essential component of family centered care, and that family centered care evolved into family as a discipline.

And as you will see in this series that there are many types of family involvement off which are part of the fabric of LENDs and not just a decorative fringe.

. In 2011 Ruth whoppers from the center in Memphis posted an important question and said, "I wonder what impact family involvement has had on all the LEND trainees." To do this the Family Involvement Survey was born.

The survey was started in 2012 and it continues and participation is voluntary, but we ask all graduating LEND fellows to comment on the importance and impact of family involvement, and to that end we identified eight different types of involvement.

The survey became the fabric, not fringe White Paper and is all based on survey information. Next slide, please. If you have not seen the White Paper we look at a different types of involvement and include for each type the definition, description of types of programs it is best for, discussion of the need for that type of involvement is all is the benefit, Resources for Implementation as well is strategies for implementation, looking at some barriers that might arise and strategies for addressing the barriers as well as evaluating the success of that involvement.

Although we call them one pagers they are in fact 3-4 pagers. Next slide, please. The different types of family involvement include Family Members as Faculty and Staff, family members as support in clinical settings, family members as mentors, as presenters and door panels. Family members from community serving on advisory boards as research participants or consultants on preparation. Family-focused topics, families as trainees, and lastly family members participating in program planning, implementation and evaluation.

Next slide. Now, I know that many of you are familiar with LENDs because you are here from LENDs but for those who may not be LEND is funded through the maternal children health Bureau and

advanced level interdisciplinary leadership training program and family participation is required in LEND programs, however,, when we think about family participation we tend to think of that is family faculty and we have had family faculty in LEND programs as early as 1992 or family trainees, which we have had as early as 1995.

Also, mentorship programs. But indeed there are other possible roles.

Next slide. We really feel that there is value for family involvement in all professional training, and so the active participation of family isn't uniquely suited to LENDs it has a fundamental role in all training and the purpose of the White Paper was to share lessons learned from LENDs with other training programs as a means to encourage and strengthen family involvement. It is always important to remember that when we are talking about families we should be talking with families.

So today Dori Ortman will be discussing family is training and discipline, faculty and staff and also be talking about families as presenters and/or panelists during training sessions. Next slide. This is just a little graphic with our schedule. So the first session which we had last week has now been archived and is available on the AUCD website, and we have two sessions after this one. When on May 24 and then concluding our four-part series on May 25, and that this time I am thrilled to turn this over to Dori and let us talk about Family and Training.

DORI ORTMAN:

Thank you so much, Fran. I am Dori Ortman the family faculty with the LEND center in Pittsburgh and training director and this is my 10th year as family faculty in Pittsburgh and I have been thrilled to work with the LENDs under Fran's amazing leadership for many years. And I am also happy now to be a part of the hearing -- Steering Committee along with the cultures and also very happy to be a co-author of the White Paper and will share it with you all is webinar, so today we'll talk about two of the eight different ways that Fran had mentioned that be identified as a network for family members to be involved not only in the LEND training but in delivery of education for various training opportunities and professional opportunities for family members.

So in keeping with the various categories that Fran had mentioned, first the definition. The definition we think of family members serving as faculty or staff as a part of the training program, we are really talking about family members of individuals with disabilities and special health care needs specifically recruited for employment, and end up typically holding appointment positions designated as either family faculty, such in his, but also can be other titles as well. Throughout the network many families work in different capacities including some of the titles you see there. Family faculty, Family Discipline Supervisor and there's a lot of different roles family members can play when specifically recruited for employment as part of the training program and can fill a lot of important needs that program may have such as creek incorporated -- coronation, mentoring or discipline training or other training as well depending on the program. We are trying to think about a wide variety of training programs and in

thinking of families participating in mentoring other employees, other staff or other professional trainees and also as a liaison to families participating in clinic and families coming to clinic, all of the LENDs have some type of clinical component to them so when thinking of healthcare or educating healthcare providers or future healthcare providers, how families can play a really important role and is mentioned, our last webinar which is archived and available specific to family supporting clinical trainees and settings and so if you hadn't had a chance to look at that that is something the way I do take a look at the archives as well.

Next slide please. Again, some of the ways that we think of the eight different ways for families to be included in training programs we thought this particular Avenue was best for programs that possibly our newly funded and require the addition of family as a discipline or faculty and as mentioned, our LENDs are funded by Maternal and Child Health Bureau and family participation is a requirement as Fran mentioned, so recruiting family members is something that LEND has been doing for a number of years and has gained a lot of perspective do that, so there possibly maybe other programs that it is a requirement for families to be involved, and we think that is great. Also programs demonstrating an interest in enhancing the roles of families.

It is well proven the values families bring to trainees programs that can be accessed in number of years of data collection through our Family Involvement Survey and families absolutely add value to training programs, and any program that failures at role and was to recruit them in an employment position this is the type of support you could expect from families and also programs that currently employ family members as staff, that are seeking guidance in how to expand family members roles in training and possibly in a higher position or moving to a faculty position, in a university or education based program.

Our discussion is made as most of us know family members are important and really a critical part of any interdisciplinary care team and health education programs. This was mandated, as mentioned, by the Maternal and Child Health Bureau in 2005 and family been recognized as a formal academic discipline under their funded programs, and the reason that came about was because they wanted to increase the emphasis on family centered care, and if you're going to talk about family centered care who else is more effective than family members, so that did become a mandate under their funded program and we are so happy that it did, and it certainly has increased as family-centered care and families are a very effective way to establish education in various content areas that truly are critical for professionals working in their future careers with individuals with disabilities where they are able to learn firsthand with family members the various needs that families have when you are think about family-centered care.

Some benefits. Gaining knowledge about family issues is best through real-life experiences. The LEND discipline network is comprised of family faculty and other family-based staff and LEND

programs across the country and continue to increase our membership dues that maternal child of healthcare requirement and based on first-hand experience to provide a family perspective injures that family centered practice and ensures competency in our training program and is shown a very high impact of the importance of family faculty and family members is trainees, learning alongside clinical trainees, and an additional benefit is the family faculty have so many connections and tend to be the most experience in navigating service systems, so when thinking of other disciplines that come to the table in a training program the training may have experience in certain service systems, but families are truly ones who had to navigate service systems across many areas and truly bring that experience and knowledge to the table.

Families are very connected to resources and support that may not be known by the training program and come across other families for various supporting roles, which we will talk about in a little bit, and we will talk more how family faculty can really help to make that happen as well.

Family members are engaged in family advocacy and in Pittsburgh advocacy is a very important competency and is family members, but that experience in navigating service systems they also come with experience in engaging in advocacy activities and real please -- play a huge part in having others recognize advocacy.

Next slide, please. Back one more, sorry. I'm sorry. Again, benefits and family members are most likely to provide a family perspective to ensure family-centered care and we talked about access to other family members and other family related components to the program.

Some of the other benefits or content areas that families can provide experience and knowledge on, family and professional collaborations. We have been working with professionals throughout our lived experiences with professionals, doctors, therapists and other service providers so we developed a family professional collaborations and we can help other trainees understand how best to foster those relations and collaborations. Of course, family support, who often tap into throughout our experience with our loved one with a disability, and we are able to help other trainees the importance of navigating those systems, and Family Quality of Life and I am trying to see the other side, program planning, implementation and evaluation.

We love evaluations and we love surveys, but it is really important we want to make sure we are making an impact. We have seen over the years that we are and were really happy to be sharing some of these ideas and processes we have put into place and help other training programs recognize the importance of families.

Next slide, please. This is a message to sort of demonstrate some of that value that trainees gain from having family faculty specifically to family faculty in one of our LENDs programs and I wanted to thank

you for this opportunity and be the best mentor ever. I feel so empowered and inspired and I hope I will feel this supported and encouraged. To refer to my pre-competencies document and is pretty awesome to see I learned exactly what I had hoped to learn. I am so grateful.

This is from one of the LEND trainees who had influence and mentorship from their family faculty member at that particular program and what that trainee took away and she felt added value to that training.

Some Strategies for Implementation. When we think about programs and taking this on an editing family members or recruiting them specifically for employment, and recognizing the benefits that can add to the program. We now want to think about strategies for making that happen positively and professionally. Some initial steps can be related to think about developing and implementing curriculum, resources and training material and a family member can be crucial when looking at the competencies you want your trainees to take away from this, and that experience and knowledge and lived wisdom that family member has gained, and how they can incorporate that into training materials and the various resources that they bring.

Recruiting and supervising and coordinating the discipline and family discipline trainees are specific to LEND although they certainly exist in some other training programs as well, but for any training program when you think about adding family involvement in the way that families can add value to that, they really can influence other trainees and perhaps interns that you may have in any volunteers that you have working with you.

Serving as a team member initiative is a great way, and make sure your grant initiative looks really well if you have family involvement and support around that. We talked about serving in clinical settings, and take a look at the archived webinar Part one about clinically supporting families, collaborating on local and state disability networks. To families have adequacy experience and how they can add great value assisting in research. Families are always valuable in research and any research programs. Directive approaches to policy and systems, again, I think that is self-explanatory. Family-centered care and person-centered care. When we think about systemic change and tell that can possibly happen and how you may want your trainee to go out into the world and make that happen and families are really the ones to guide them on how best to do that.

Other considerations that cannot go without saying is credentialing. Various credentials for at least our family faculty, but thinking was sort of level of experience do you already want someone to have when they come to the table? That is an individual program decision. Budgeting and how that will be funded when recruiting someone for employment. Thinking what kind of package you put together and where the funding will come from. All the LENDs across the country are working with families so connecting with them and other institutional organizations that do have family as part of staff, and other support -

related roles. Maybe the program isn't quite ready to have a family member in a higher level faculty or higher level position, but what other related roles could you maybe bring them into and sort of further involvement from their. -- There.

What barriers may you encounter when hiring a family member? Some of the barriers that you might want to think about is certainly a recruitment of qualified candidates as faculty or University staff is a process involving targeted outreach, and that may be new to an organization. Developing relationships with perhaps new and different channels that may require forming new alliances that are unfamiliar to program the organization, but just know it will be worth it in the long run.

Again, salary we talked about. It might be an issue and particularly if the candidate doesn't hold as much maybe educational degree as other faculty or similar levels of leadership. These are some things to think about when you add a family and think about what experience you want them to come with.

Evaluating Success. When you add family members how do you evaluate if that is beneficial for your program? Some examples you might want to think about when you talk to others in an organization is how well the family did acting as a professional leader and advocate? Developing training materials. You can see some other ideas when you think about how well do these areas go with this family member incorporated as part of yourself, and also measuring the achievement of all the working objectives the organization has in bringing family involvement into it, and how well did go and how will you measure that achievement is what you may want to think about when evaluating.

That was little bit about Family Members as Faculty and Staff and now we would take a few minutes for questions and answers and I'm happy to answer any questions. Fran is happy to answer any questions, but we would love to hear from you.

EMMA FOX:

Feel free to put your questions in the chat and you can come off mute. I see Brian your hand and we can get this started.

SPEAKER:

Good afternoon. Brian. Arches, autistic self advocacy coordinator in the school of medicine and Children's Hospital. The importance of family members cannot be overstated. I have those titles and I do that work because I am following in the trail of family advocates, so I just wanted to thank you for being here and putting this presentation together and for giving it. It is a new gold standard that funders, including the federal government, require places like a school of medicine when they are doing healthcare training, interdisciplinary healthcare training, that a fellow member of person with the lived experience of disability must be a part of that curriculum. That is a beautiful standard and it is our

privilege to take advantage of that not only is family members but is people with myself as advocates as someone who was with a disability, and up-and-coming doctors, therapists and providers and administrators they get a chance to dialogue very openly and frankly as part of their required curriculum, so I thank you very much.

DORI ORTMAN:

Thank you, Brian, and so will stated, the gold standard. I love that. What more can contribute that it is required by federally funded programs that family members be included. We are glad that you are on board with us too, so thank you for that.

SPEAKER:

Hi, I am Susan from the University of Washington LEND program of family and I was writing my question in the chat it is kind of long. It has to do with the idea of a family member looking for a paid position. Looking for a job within connection to the LEND and what it looks like to look at applicant on their qualifications as a faculty or some other paid capacity, and so, you know, in addition to being a mother of a child with a developmental disability. I have a Masters degree in education, a certain amount of culture? Well, I am white and college educated and an English speaker. The question is I am not sure that having another voice of a privileged white person with a higher education – sure, I would love a job with LEND, the kind of voices that may be underrepresented at the table are folks who may be more marginalized, so I'm wondering what there is in the thinking to say maybe there's a different criteria and what makes an excellent higher for family and somebody that has necessarily a competitive curriculum vitae. I making sense?

DORI ORTMAN:

You certainly are to me. The first thing I would say and I am thinking from the LEND perspective and they all have their own policies on credentialing that they want to see, and not only families and employees, but even his trainees. Our family trainees we bring in we are looking for a certain level of experience, but all the LEND centers across the country have different variances around that, so not all are looking for necessarily a certain level of education.

Some do require various levels may be an Associates degree and maybe a bachelors. It is so varied across the country, but many, many are not looking at that level of education. They are looking at with the family brings to the table as part of the family perspective, and that lived experience, some of the things we mentioned is how they navigate to the system, along they've been doing that, what that looked like for them and what advocacy efforts they have been involved in, and things like that, so it is not always that sort of cut and dry like you mentioned a white woman with a Masters degree.

I know throughout our LEND discipline network our faculty members across the country, our network is usually, usually diverse, and we are very proud of that, that there is a very diverse population



throughout our entire network, and hearing and bring those voices to the table is family faculty across the country that is usually beneficial to all of us.

FRAN GOLDFARB:

Dori can I hop and of that, because I think it is a very important issue? Susan, thank you for raising it. Do tend to be a somewhat white, female group, but I also want to point out that most of us are first generation family faculty, and we tend to be a fairly stable group of people.

I have been with my LEND program now for 24 years and so what I see is that maybe we were the ones lucky enough to be in the position to be able to take on a job like this as our LENDs were developing a programs, but I think as we start to look at the second-generation of LEND family faculty we will see a lot more diversity, because our trainees are a very, very diverse group of family leaders.

DORI ORTMAN:

With me been with LEND for 10 years, I don't know if I would be considered second-generation yet, but between Fran's 24 years and my 10 years, absolutely have seen more diversity being added to our network over more recent years, and his friend said starting through the training network, but I am definitely seen diversity added to our network.

Great question. It is very important to the AUCD overall as well.

EMMA FOX:

This is Emma, I will add this is an endeavor and a topic and found that AUCD is really passionate about, and you can expect to see resources not only to the family discipline, but to all disciplines not only in LENDs but in all corners of the network as we progress throughout the next couple of years, and I would be happy to point network members in the direction of our amazing resources, but in the interest of time I would recommend remaining questions are responded to in the chat box and we go ahead and move on to our next section.

DORI ORTMAN:

Thank you so much and for the great questions. We will absolutely get to the questions in the chat box and I'm very happy to talk via email. Again, another one of those eight areas addressed in the White Paper is family members as presenters and panelists and is something that has been very important, I know in our Pittsburgh promo, but in all the LENDs programs across the country and we wanted to focus how that can also be very useful and helpful to other training programs and professional programs as well.

Brian B stated this almost exactly this cannot be said enough how crucial the unique experience a family member can bring to a variety of settings. It is consider, as Brian said, the gold standard, the

best practice in disability standards and it cannot be said how critical it is to the creation of any practices within a program, with any health service provider and policies as well, and we will talk a little bit about that later but it cannot be learned at a university course and the role of a family member or a parent of an individual with a disability, that is not something that can be learned at the University course. It must be deliberately incorporated as an invaluable asset to any program, and understood that it can be learned from any University or anywhere else.

Having families as presenters splash -- presenters or panels or speakers, it is considered the gold standard and it is best practice, so if that is what your training program values, you educational program, this is a way to go about that. This is considered best practice.

Family-centered care, who better can bring that perspective better than a family. Impact of disabilities that cannot be learned anywhere else and programs that value competencies that families provide and we cannot say enough how valuable that is to any program.

The discussion of need is beyond measure and truly puts a "face" on disability. Family members no matter what the audience is or what training cohort or professional program, any type of service provider, it really helps those audiences to focus on children and their families. Not diagnoses and symptoms, which we so often tend to do and I've been working with families over 20 years and I am also a parent to two children with diagnoses, and I as a professional, can get sometimes caught up in diagnoses and symptoms, but I have to remember to take the family perspective and bring that in and it helps to place more emphasis on family-centipede care.

And it provides a powerful voice to influence program decisions, so have family is presenters and panelists is really significant in providing professionals with the motivation they need to keep that work focused on the real needs of children with disabilities and their families, and that is what can really spark ideas for different types of approaches and interventions, and how to influence those systemwide decisions.

Next slide, please. This was a question I wanted to have a little bit of interaction, but if you would like to put some ideas in the chat box, because this was open to a lot of different ones, but what might be considered a benefit of family members sharing their perspectives? I'm going to mention a few more in the next slide, but before we go to that, what might be considered a benefit of family members sharing their perspectives, and if you want to put it in the chat. Anybody want to contribute in chat?

EMMA FOX:

We have a hand raised and if folks want to come off mute feel free to share.

DORI ORTMAN:

People learn through stories, absolutely. The ability to help up and coming doctors and dentist. Learn what is really like caring for someone with a disability. Awesome.

SPEAKER:

This is Brian B. May I explain my comment?

DORI ORTMAN:

Absolutely.

SPEAKER:

I put in the comment is the only people worth remembering and that is not true and they're doing years and years of academia and there's a ton of value and things worth remembering, but time and time again I had up-and-coming healthcare professionals, and frankly longtime preceptors, administrators, faculty say that the thing they remembered was that family members story.

And if you look at the human psyche and all team dynamics in history, that is how we are made. We learn from stories. That is how we exist and go from fabric to fabric and person to person by having an identity, so coming in and sharing your story, your voice, it is gold.

SPEAKER:

What I put in the chat, we have been doing medical school trainings for years and I was doing it with Barbara Levitz when she was family faculty at LEND and I know in July 2020 it was mandated across the country that all dental schools have caring for disabilities added to the curriculum, but it is still not mandated. It is hard to believe in this day and age but speaks to the critical importance of parents and families telling their stories.

I know this year and last year virtually we were able to train medical students virtually and 12 breakout rooms, to continue the practice and it was families telling their stories. Parents and individuals caring for individuals with disabilities, and the impact, we get the feedback which is great, so really speaks to everything you are talking about.

DORI ORTMAN:

Thank you, Karen, you are right and it is not mandated yet. In Pittsburgh we provide training to a medical school and dental school. We have dental school faculty as part of our LENDs as you mentioned, we've been doing it for a few years, but that is up to an individual program, and is not a mandate quite yet. A lot of our programs do that though.

SPEAKER:

That's great.

DORI ORTMAN:

And I agree, it is something to be considered. If you are with a program that is not participating or taking an initiative to do that that may be something you may want to bring up. Thank you. We are going to the next slide so we can continue on.

Any presenter can share knowledge, or the understanding that they have gained from their education, but family members share true wisdom. It is not just knowledge. It is true wisdom which only comes from the experience from their journey, from that lived experience that has impacted them.

Well told family stories, and what they can do, and I saw some of that in comments as well. Family stories are so powerful, and the ones that most people remember. They make the most impact, they can touch hearts, they can change minds. Audiences receive the encouragement and motivation that they need to continue in the work. It empowers them to continue this, and it gives them that motivation to find new and creative ways. Well told family stories have the potential to impact policy. That is part of our curriculum.

Our LEND Center of Pittsburgh get sent to legislators and we help them create that powerful story, because that is what legislatures want to see when they are looking at policies and bills.

However, you can incorporate family, I encourage you to do that. Next slide, please. A couple more quotes, in case you did not notice, I really like incorporating quotes. I also like incorporating more interaction, but time does not allow for that, so my apologies.

A real perspective of what our lives look like at various times, because families and their lives are changing. And so this particular family journey over the course of a year over this woman's training felt they could give clinicians perspective felons into their life, and on the other side, the next quote from a LEND clinical trainee and blood that may have looked like for them to get that LENDs into the real journey of a family, this quote (Reads) were LEND family trainee impacted me greatly. I learned the importance of valuing each caregiver and his or her perspective and to always remember they are the expert of their child. It was amazing having an actual family member be with the clinical team to be there to support the family we were seen.

LEND acronym is leadership education and this clinical training is going to take that experience and I do know who the quotes are from and from which program, and they were female, but I do know these happen to have, from two females. She will now be able to take that into her future profession and discipline/career and, hopefully, use this experience to catapult her into a level of leadership and being able to have that different lens in her career just as a family training was allow her to view through that lens what life is like for a family with a child with a disability. I just think those two quotes are very

powerful.

Strategies for Implementation. Many programs successfully include faculty under trainees and there is a variety of ways that programs could do that. Some effective methods we have seen is to start with an existing individual, within the organization, that has personal experience with disabilities.

We do talk a lot about parents and caregivers, but we also have siblings, and sibling experiences. We have had grandparents. Think outside of the box of family members of a child? -- With a disability, and see who is willing to come and provide that perspective, so that's a great way to start with someone to effectively share their story.

If you have a curriculum and you want to think how families can more effectively share their stories, learning to effectively share one story into the curriculum as a competency can be really, really helpful. There are different resources that will be provided as well that can help individuals who wish -- who are family members who wish to be presenters and speakers.

There are some great resources how family members can effectively share one story, especially in advocacy, but also to a variety of audiences. Hopefully, you will look at those with the way purses -- resources we provide. A panel of parents/caregivers/other family members, it could be a project or existing employee or existing training to perhaps put together a panel of families they might know or it could be something that management takes on because they want to bring on a panel of parents to come and talk with their staff or their professional programming that they're providing.

Some things to keep in mind when organizing a panel, have set goals for the panelists. As family members, we can really go on and talk about our kids. It's helpful to set goals for the panelists and we encourage them to share two or three take away points. So it is very simple. If the family members -- if panels or future medical providers allowing the family 10 minutes to share their story and 10 minutes to share ways medical providers could have helped their families better or three ways medical providers were a huge help to them, or however, you would want to organize it. Give very specific goals to the panelists.

Family members who have children with special health care needs or disabilities may be on a super tight schedule, so consider that. When having several speakers for any type of a panel, it is really important to have a variety of experiences. There should be a cross-section of age ranges, there's types of disabilities, different social economic status.

Families can be on a really tight schedule, so make sure you give them enough time to prepare. Especially when trying to provide a lot of different types of families, and families from various areas of life and sometimes transportation can be really challenging for families. If you are able to get cars.

Make it very clear that families are the experts.

That is to the audience. Some audience may have misperceptions and they might be kind of like but it should be made abundantly clear to the audience that families are the experts within their own disciplines. And presenting a family story can be emotionally charting and difficult memories may resurface, and fears of the future may arise, and sometimes we have had presenters that start crying.

The audience should be understanding but never respond with PD. Maybe have some tissues ready. And Evaluating Success. Consider the impact from the presenter perspective and also the audience perspective. Be sure to talk with the presenter with the family member to ensure how it went and so they can take that feedback and continually build up that story to be able to effectively share this story and make the most impact, and allow presenters to progress from smaller audiences to bigger and from smaller to broader.

Family members should prepare focus questions for feedback. Such as to their story make logical sense. What were the take waypoints. -- Take away points.

Resources for Implementation. This will be archived so you will be able to access it with one click, but just know that they will be there for you. Do we have time for questions and answers?

EMMA FOX:

It is 4 o'clock, and if you need to hop off you can do so. Myself, and Dori, if you have a few minutes to stay on the line to answer questions, but otherwise thank you so much for joining, and please fill out our evaluation that you can scan with your phone on the screen here, or by the link in the chat, thank you so much everyone. We hope to see you at our next webinar.

DORI ORTMAN:

Thank you everyone for your attention, and feel free to contact me via my email. Thank you for your attention.

SPEAKER:

It is Karen. Great presentation. Excellent, so thank you. When you were talking about panels, we do a lot of panels, so we believe wholeheartedly in that. We used to do pointed questions for families to answer and recently we started doing panels that were impact on policies, and I think it was impactful because you think of things like all sort of federal and state and how does it really make a difference in real-time for families? And the feedback from trainees has been very strong that they are learning about these policies and how do they really work in practice or how are the challenges or barriers to practice and learn about family stories, so I agree with you.

Our best feedback at LEND have been from sibling panels and nothing like person first.

DORI ORTMAN:

Absolute. Again, you cannot learn that at any university class. Experiences like that. That is an important part of our stool and the -- also and they have to learn about advocacy message and learn how it impacted them and create a message, and all of that is really important and powerful and understanding that how those absolutely impact families. It is great to hear you are doing that also. There are some really great ones that we share with all of our families who will present on how to effectively share your story, and there is some powerful points, so if you haven't looked at those I highly recommend them.

SPEAKER:

It is in the White Paper?

DORI ORTMAN:

Yes, and in this too, if you click on the link on the slide.

SPEAKER:

Thank you.

DORI ORTMAN:

Thank you, Karen. Always loved talking with you.

SPEAKER:

This is Brian, I will chat you briefly. Tell me again how I can go to the link related to in the White Paper you mentioned effectively sharing your story?

DORI ORTMAN:

If you want to go to the resource list I know there are some there. There's an action information sheet. Ways to lead change to telling your story is another fabulous one. All those are great, and we have family competency also, but those last three are great., Is the link active within the White Paper on the website as well?

EMMA FOX:

Yes, it is. I can hyperlink that in the chat now.

DORI ORTMAN:

Thank you, Brian, so much for your comments. They were so great and so will verse. I really appreciated the addition of them into the presentation as well.

SPEAKER:

Thank you. It's a privilege to follow the generations of wellness and advocacy that has been done, and to carry it further.

DORI ORTMAN:

Thank you. I can tell that you are passionate about it and will continue to do great things.

FRAN GOLDFARB:

And thank you for not calling us old, Brian.

DORI ORTMAN:

I am glad you said that.

SPEAKER:

Anything else we can answer for folks?

DORI ORTMAN:

Emma, if anything is in the chat will you follow up with me?

EMMA FOX:

Yes I will post just to the chat and if someone shared a resource.

DORI ORTMAN:

Thank you, Emma. I did not want to ignore anyone because I did not get to read everything.

SPEAKER:

You put in three links on that last one, and the third one is a hotlink, but the other two are not. Just thought I would let you know that.

SPEAKER:

I typed those in, Brian, and I think that is why they are not hyperlinked.

SPEAKER:

In some documents you have to hit space first. I'm going to go finish making lunch. Thank you for being a part of my lunch making time.

DORI ORTMAN:

When you go to archive this, I know I had a little hiccup? I think in the first presentation, I don't know if



it was the benefits, there were two slides on it, and they were reversed, and the next one said Continue, but the continued one was first. That one should be after. That's all. It threw me off a little bit, just from my notes. When you archive it you may want to switch them up.

FRAN GOLDFARB:

I think it went beautifully.