

Live captioning by Ai-Media

JACKIE CZYZIA:

Hello and welcome everyone! We are just going to wait a few more minutes to allow people to join and then we will get started. Feel free to introduce yourself in the chat by name, program role...

Thank you for everyone who is joining just now. Again we will wait one more minute as people join. If you are just joining, feel free to introduce yourself in the chat, what program you are coming from, your name, your role. Happy Thursday!

Alright, I think we can get started. Hello everyone and welcome, my name is Jackie Czyzia and I am the senior manager for the maternal child health technical assistance team here at AUCD. I am very happy to have Mark and Molly from the GSU with us today for the third time as part of our training series, today we will talk about advocates as trainees. And we are very excited about our partnership with GSU.

Before we get started some housekeeping items. Please ensure your name is displayed correctly in the participant list. You may also include your program or organization name, and preferred pronouns, if you are comfortable. For example, Jackie Czyzia, AUCD, she/her. To do that, hover over your name in the participants box and select more and rename. We ask that you please remain muted and less speaking, and please state your name prior to speaking. Live captioning and ASL is available, for captioning there should be ACC box at the bottom of your zoom screen, you click that and should be able to access it. If you have any trouble, you can contact me in the chat.

Again, use the chat to introduce yourself, your name, program and role. Just to get us started, to know who is in the room, we would love to do a quick poll. That is who is with us today, LEND faculty, training Director, Director, self advocacy faculty, self advocate, current trainee, former trainee, other MCHB training programs and you may select all that apply.

We will give it a few minutes...

Alright, about 55% of you have participated. Give it a few more seconds... 68% of you, 70... Alright, I think we can end the poll. And share the results. Great, it looks like we have some LEND faculty, some training directors, LEND directors, a lot of self advocacy faculty which is terrific, and some self advocates themselves. And former trainees, and other, if you do not fall into this category, for free to introduce yourself in the chat if you have not done so already. Without further ado, I think we can stop sharing the poll, I would like to introduce both Molly Tucker and Mark Crenshaw from GSU.

Molly Tucker is the training and advocacy manager at the Center for leadership, I think my screen is frozen, apologies for that, Molly is the training and advocacy manager at The Center for Leadership in Disability at Georgia State University. She is responsible for the facilitation and the coronation of leadership development and self advocacy programs for individuals with intellectual and developmental

disabilities. She is also a member of the Georgia LEND implementation team and in this role she supports advocate trainees, and focuses on ways to incorporate universal design for learning into all training components.

We also have Mark Crenshaw, Director of Interdisciplinary Training at the center for leadership -- Interdisciplinary Technical Assistance Center at Georgia State University, since 2011 he has been responsible for the implementation of Georgia LEND. I will let them take it away.

MOLLY TUCKER:

Thanks Jackie, I will go ahead and share my screen, and let me know if you can see everything correctly. Alright, can you see the slides properly? Perfect, thank you guys for having us again, it is been a pleasure to work with you guys over the past several weeks, as Jackie said this presentation is called Advocates As Trainees, and so here are today's objectives, number one... Participants will be introduced to the new LEND requirements regarding inclusion of self advocacy trainees. Number two, participants will be introduced to the self advocate trainee and faculty roles. Number three participants will understand the differences between discipline specific and interdisciplinary training, and lastly participants will be provided recommendations for recruiting and selecting self advocate trainees

Again my name is Molly Tucker and I am joined by Mark Crenshaw, our first question for you guys is actually a pole, you will see a pop it up on your screen in a minute, but do you currently have long-term self advocate trainees? That is our first question for everyone. If you would not mind launching that pole for us.

About half of you have responded so far, and I see that at this .70% of you say yes you do have long-term trainees, that is great to hear. We do have some that said no, we do not or only have shorter or midterm. That is completely fine as well, that is what today is about as well, how do we get to the point that we have 300 hour trainees as part of our cohorts. You can go ahead and and the poll.

I will turn it over to Mark to do our introduction, and I want to make a point to say that anything you see from quotation marks is taken directly from the notebook, so please note that anything we took in quotations, we took directly from the guidance, so if you have questions about that let us know. Mark over to you.

MARK CRENSHAW:

Thanks Molly, we really did, when preparing for today, we really wanted to spend some time talking about the requirements to include self advocate trainees and to have a self advocate faculty by the third year of this LEND cycle. And much of what we are going to talk about next is specifically taken from the notice of funds, and so the first bullet point under specific objectives in the NOFO states that program should "train graduate and postgraduate students, family members, people with disabilities and community professionals."

I remember when we started including self advocates in our training program, and there was a conversation with our project officer and she said to us, "you guys do realize that the guidance says you are supposed to be offering a graduate-level -- graduate equivalent training expense for stock" and we said yes that we realized

that.

So we wanted at that point, to make sure that we were offering a graduate equivalent training experience that was accessible to people with disabilities. And that is kind of the content of the first two webinars, how we have gone about doing that. But just wanted to highlight, these are the kinds of folks who ought to be in your LEND training program, and that people with disabilities are officially a part of that, as of year three of the cycle.

And then, the requirement says "by year three of the project, each long-term training cohort must include a person with a disability as a self advocate trainee. Self advocates participated in LEND will build upon the skills and knowledge acquired through their lived experience with disability to develop and enhance their leadership expertise and share a disability perspective with other trainees."

So on the next slide we have sort of highlighted a few phrases from that... Am I right Molly?

MOLLY TUCKER:

You are one side ahead but you are OK. We will do that in a second. As Mark said, we wanted to make sure that everything we mentioned today was directly from the guidance, so it says that "self advocate/individuals with disabilities including those with intellectual disabilities" is how we are defining self advocate trainee. As Mike said they need to demonstrate readiness to develop leadership skills and share disability perspectives. No educational minimum is required for an individual that identifies as an advocate trainee. They do not have to be enrolled in any academic program. But it is said, they are considered long-term trainees, so they are expected to complete the 300 trainee hours.

This is again, taken directly, we wanted to make sure it is provided in bullet points for all of you to access. But then as Mark said, this again is the definition, and the expectation for year three. We want to highlight three phrases from this, but we used to really help us determine whether or not to trainee is really a good fit for our cohort. I will show you what the three phrases are, then we will talk about the questions we ask of trainees to determine if they are a good fit for our LEND or a good fit for LEND in general. The first thing we look at is "build upon the skills and knowledge", the second we want to highlight is "to develop and enhance their leadership expertise" and lastly "share a disability perspective".

The way we are going to do this is I will read through the questions that you will see on the slide, and then mark as our training director is going to talk about why these are important to us. So for the thing that we consider when selecting self advocate trainees under the category of built upon the skills and knowledge, number one, does the individual have an understanding of self advocacy already? Number two, does the individual have explained advocating for themselves and/or others? And then lastly, does the individual recognize the importance of speaking up for themselves and/or others? That is our first set of questions that we ask and mark you want to talk about why those are important to us?

MARK CRENSHAW:

Yeah, thanks Molly, from our perspective, for us, LEND is not the first step in advocacy training for the self advocates who end up in our LEND programs. So we do want to ask questions about where they are in terms of their understanding of self advocacy, and the movement from self advocacy to advocacy with and for other people with disabilities.

In the context of that, one of the sort of questions that happens for me, is for instance, if they are an autistic self advocate, are they going to be able to develop a perspective of broader advocacy, and potentially partner with other advocates? Partner with allies? Be a part of broader coalitions? That advocate with and for a wider range of people with disabilities and their families? And their allies?

What we are looking for in the context of thinking about these questions, like I said, A, that progression, and B, are they going to be able to think about themselves as a part of a larger disability movement? So those are really the two things. In terms of those questions.

MOLLY TUCKER:

Thanks Mark. So this is the second phrase that we pulled out, this is "develop and enhance their leadership expertise." So when we are looking at trainees one of the things we look about as does the individual already demonstrate leadership skills? Does the individual want to enhance their leadership skills? Are they interested in learning and developing those skills further? Is the individual interested in learning how to utilize the skills within the disability community is Mark just mentioned? Lastly is the individual comfortable receiving feedback and mentorship as that will be an expectation throughout the program... Mark, anything further you want to talk about for enhancing leadership expertise?

MARK CRENSHAW:

I would say, Molly is probably tired of me saying this, but the L in land is about leadership, -- L in LEND is about leadership, some of the recruitment of all of our trainees, in their application process, in their interviews, we are asking questions about their readiness to take on leadership and leadership perspectives, so that is the same for our self advocate trainees.

We are not simply, the bar is pretty high... In terms of their ability and willingness to see themselves as leaders, and part of that is openness, because lots of folks from across disciplines do not know that they are on the cusp of being able to think of themselves as an emerging leaders but that is kind of what we're looking for is rare in those conversations with advocate trainees, do we think there is a pretty reasonable asportation that this person is ready to take the next up on the leadership journey?

[Us_Daune is Live]

MILLY TUCKER:

The last phrase we put out a shared perspective. This is sharing your personal

experience with others. Will they be other to comfortably talk about that in the environment. Does the individual understand and recognize their experience is not everyone's experience and lastly is the individual willing to learn from faculty presenters, and their peers and others with disabilities. Are they prepared to learn just as much as they are prepared to teach.

SPEAKER:

Creating and learning environment with everybody teaches and learns that is what this is really about for us. Is this person willing to share their experience in a way that others can learn from them and about them and from them and are they willing to listen to others in such a way as Mike to enhance their perspective on what others contribute to their learning.

MILLY TUCKER:

I will tell you guys now that you will see 5 slides all of which are titled training reflection. These will not be in the slides that you guys received. This we will send an updated version out but we were not sure initially that we wanted to make everybody's personal information shareable so you will not see these if you are following along. What we will do first is share a brief clip from a video made by one of our now staff members, Darian. He was an advocacy training for us last year.

So this video initially was talking about a pipeline program with the mind voice participation that prepares individuals with intellectual and developmental disabilities that to be on board directors and decision-making force in their communities.

Her asking them how that experience helped him and one of the questions is one of the things she did after my voice was to participate in Georgia LEND. I wanted to show you guys what he said about the benefit of having a foundational understanding of that before they joined. This video is about 3 minutes in length so I will play this for you.

(Video plays)

SPEAKER:

What I know is how did my voice prepare you for LEND?

SPEAKER:

How my voice prepared me for LEND is my voice is to me a very is like Georgia LEND which is? My voice talks about advocacy and professionalism and draw operating this and how to show you what it is like to be on the board counsel or advisory Council.

So my voice is more advocacy based and Georgia LEND is more in-depth so with Georgia LEND we talked about disabilities and advocacy as well but what did disabilities we dive deeper like research behind a disability. And how some people go to test if they have a learning disability we also did one project that I will not forget. When I was in LEND we did a parent project and we had meetings with the parent that has with the child of an intellectual developmental takes a bit disability we asked them questions like how do they operate during the day and what are some things that

they do to help that child have that life experience and what are some fun things that you do. Just to see how they operate through their day-to-day and how many people they have in their house helping each other and see how they go about their day.

So Georgia LEND is more impactful. I will say my voice is just? I'm not going to say simple but it gets you ready for Georgia LEND. So for me I'm happy that I did my voice before Georgia land because I got into Georgia land first and then with my voice I would've been backwards. I would've been like that this is a lot of information then going into my voice. It's a lot of information and it's all about advocacy so I think anyone who wants to do Georgia land I would say do my voice first and then go to Georgia land because they are hand-in-hand but one is more an in depth than the other and the other one get you ready.

MILLY TUCKER:

I hear you say my voice introduced you to these topics and LEND helps you learn more about them in detail, is that correct?

SPEAKER:

Yes.

MILLY TUCKER:

Dena I saw your question my voice, my participation, my board is a program we have in Georgia funded fire department with development of disabilities. I serve as the training coordinator for that program so we prepare individuals to be on board and advisory councils and decision-making boards and it focuses on experiences building advocacy skills top-rated professional skills to help them feel comfortable walking into spaces whether voice needs to be heard.

For us that has really become a pipeline opportunity so people can go through that program and if we feel like there are a great fit they could be considered. But for us we thought this video was helpful because as Darian said it was helpful to have something else before he immediately jumped into LEND. Just as a reminder will show you guys a couple of things about this. We'll make sure you have a copy of this.

Dena I would be happy to talk to about the possibility of my voice coming to Colorado.

That is not what today is about though. What you will see now is we have our additional training reflections. So we have something that I would like to say that this is Mark's brainchild. But we have a website called people of Georgia LEND. We picked pictures of the trainees and asked them to tell their story about what got them to LEND or what they did after LEND so we specifically selected examples of advocate trainees for the past 4 years or so. So we will talk about how each of these represents each one of those topics we just said. Either enhancing leadership or sharing their perspective for building knowledge and skills.

I will read their collections for each of the trainees in the markets can talk about them. Can you make fun of Mark for 2nd we went through this earlier and he got so excited when he was looking at people's faces that he is not had to see during the

pandemic. So on your screen right now there's a picture of Charlie Miller and Charlie is smiling at the camera and is wearing glasses and sitting in front of a garden in his wheelchair and he said back in 2019 in 2020 that he was interested in George joining Georgia LEND because he heard how unique it was and bringing leaders of the community together. Able to have real conversations and discussions around disability issues affecting the community we want to serve. Glad to be able to impact future health professionals to make sure they not only get the book knowledge but also the real stories and real lives of the living system. When he completes he feels like to be better prepared to talk about disability policy. Looking for to expanding network with other young professionals looking to impact their community. Charlie is a great example of leak enhancing leadership. So Mark did you want to talk a little bit about Charlie?

MARK CRENSHAW:

Sure. He's a graduate of the program here in Florida. Frankly internships throughout his program related to advocacy and has begun working in a state agency out of his IPS a program that really was really looking forward an opportunity to increase his leadership skills and broaden his influence. And gain a sharper policy lens in terms of a sharper focus on disability policy through LEND. So I think that is a perfect example of someone who came in already as a leader in our community and appropriately used his LEND experience to enhance his perspective and to build a network. And as a result has become a more powerful leader in our state.

MILLY TUCKER:

Is actually a state legislative director for DDE counsel. He is accomplished quite a lot for 2021. Start next one is Kayla so this is a picture of Kayla Rodriguez she is black and white shirt and she sitting in front of a brown wall and was in advocacy training in 2019. She said she was interested in being involved in LEND the issue would be a better advocate for people who were autistic and had more disabilities. The 2 most important things you want to learn is to be more aware and be a part of the disability and wrote a part of the community. And how to better stand up with different people disabilities like myself. Looking for already learned. I will turn it over to you.

MARK CRENSHAW:

I think the most important transformation that I've been able to witness since going through LEND and she is a board member of autistic if women and non-binary network now. I will say has had the chance to work for alongside Kayla for her state capital advocating with budget real items in late related to services for disabilities and specific bills and legislature. And what has happened is she certainly came with a perspective of an autistic woman in a space but recently grade gained a broader disability perspective during her time in LEND and has continued for sure with her advocacy beyond her LEND years. So incredibly proud of Kayla. I could say that about all of these achievements.

MILLY TUCKER:

Next is Kurt Vogel if you were here with us last week you had opportunity to hear his perspective perspective. He was an advocate training in 2016 and 17 and have an opportunity to do LEND together. A picture of him is he's wearing a green shirt sitting in friendly Atlanta skyline and says he's appreciated the Georgia people

getting to know who he is. He's looking for leaders and there's many opportunities and experiences in the Georgia Tech Excel program has opened the eyes of the possibilities exist and have open the connections to the Georgia program that he may not be aware of yet. Again this is an example of building on responsibilities he's had and with respect to others.

MARK CRENSHAW:

That was exactly what I was going to reflect on with curtain mind. He came in with a disabilities perspective that he was relatively comfortable with sharing when we started. I got to have a lot of conversation serving as the self advocate faculty with him. And just saw him embrace who he is as an individual with a disability and since then obviously has been able to support other self advocates to do that as well. So like I said he came men to LEND with a disability perspective that he honed his perspective on his identity as a person with a disability through his land year.

MILLY TUCKER:

Before we go to the first one I went to ask a couple questions. Mary asked you Mark how to advocate for particular bills? Isn't that lobbying? Can you address that?

MARK CRENSHAW:

Absolutely. Mary I would say that there is no lobbying when I am with trainees at the state capital or the capital in Washington DC. Simply what we are doing is educating policymakers educated to issues and specific legislation that impacts people with disabilities. We are not instructing our legislators about how to vote related to the specific issues. We are making them aware of the perspectives of Georgians with disabilities and what needs to happen so their constituents with disabilities in Georgia can have an increased quality of life.

MOLLY TUCKER:

Correct me if I'm wrong, but typically when you are there personally, you are there to support the individuals to have these conversations but you are not the ones having the conversations with our legislators.

MARK CRENSHAW:

Absolutely right, we are literally standing across from the chamber waiting for the trainees member of the Georgia state house or state Senate to come out and meet them. And I am typically practicing with the trainee what they are going to say when their legislator does come out. And I will be clear, this isn't just activity the undertake with self advocates trainees.

It is also the way that we work with all trainees to get comfortable talking to policymakers.

MOLLY TUCKER:

Marked the other question that came through, and we will talk about this a little later, do these trainees get a stipend and if so where does the funding come from?

MARK CRENSHAW:

Yes absolutely, the trainees absolutely do get a stipend, that is on the same level

as the trainee peers, and the stipend comes from the LEND budget. And we also, just so everyone knows, when we engage self advocates as speakers, in our LEND program in any way, we compensate them for their time. We do an advocacy mentoring experience, and all of the advocates who participate in that experience, and help teach our trainees are compensated for their time.

And we build those funds into the LEND budget. And that is a terrific question, so thanks for asking.

MOLLY TUCKER:

This is our last reflection, (Name), she is standing in an all blue outfit against a brick wall, she says "the best part of being in Georgia LEND so far as being at the table! What I love most about the program is the interdisciplinary aspect of it. Having so many representations present in one room is powerful. We get to hear each other's thoughts and opinions and come up with solutions and even months is that impact the disability committee at large. And the fact that this program intentionally asks disabled persons to the table to be a part of that conversation is very ground breaking."

So again, the ability to share perspectives is important.

MARK CRENSHAW:

Absolutely. And I will say, Rasheera is a terrific example of that person with chronic medical health issues and disabilities, and from the beginning she was very able to share a perspective about her medical and healthcare experience, as well as having been a student in special education.

And I will say, Rasheera's language, over the course of her LEND experience change. She clearly was able to find... To come to a place where she understood her disability as a source of strength for her, and is a source of pride. It is used that perspective, has leveraged that perspective to go on and do some really cool stuff, her Georgia LEND experience encouraged her to go back to school, she is now working on a Masters in Public health.

She has had really cool internships, she did the American Association of people with disabilities summer internship last summer and worked in Georgia centered John (Name) office so anyway she has a really cool podcast about the intersection of being a woman and having a disability. So just really grateful for the work that she is doing, and every time she calls to ask for support in any specific way I am glad to get to catch up and say of course we will support you! So anyway, grateful for the work she does.

MOLLY TUCKER:

One thing it does not specifically talk about is what our goals or outcomes for trainees, obviously that is individualized and cater to that individual trainee, but marked you want to talk about some of the goals that we have for our trainees? Some of the things we hope they are able to accomplish as a result of their experience?

MARK CRENSHAW:

For sure, I think the goal start with building on what the NOFO says, so enhancing

leadership skills in perspective, enhancing the way they tell their story and share the narrative with colleagues and outside audiences.

And really helping them to engage in learning and reflection, and those are consistent for the goals for all trainees, to be honest, we do not necessarily in that way have a specific set of goals for self advocate trainees. We do want to self advocate trainees to use LEND as an opportunity to increase their networks, to get a chance to listen to and learn from and speak to diverse stakeholders and diverse audiences in different ways.

We want them to connect to self advocacy in the state. And then, as they are preparing to exit their LEND year, or their time in LEND, some of our folks have done LEND over more than one year, we really do want to have a set of conversations that set them up for what is next for them. So that is a range of things, from thinking about employment post LEND, or like I said with Rasheera, applying for further study, so those outcomes for the trainees are really diverse and individualized, and we want their mentorship with the self advocate faculty, and the time with me to be spent really focusing on how we can support them to be successful going forward.

MOLLY TUCKER:

So we are not going to talk about self advocate faculty members, so again this next quote is directly from the guidance and says "key faculty members on into pleasant dairy teams should include individuals who have lived experience with ASD or a STD both personally and as family members." With is by year three, there needs to be a member of your team who is a self advocate faculty member, and some of the things they will be responsible for, will be supporting self advocate trainees, providing guidance to the overall trainee cohort, making sure they are teaching and mentoring trainees, coordinating community experiences that your program may offer, advising faculty, and being able to bring the disability perspective in the planning committee, and really being a crucial part of the assisting in planning and developing your overall curriculum. Not just there to do work for the advocate training but how are they able to incorporate that perspective into the larger program for all trainees?

Again this is all taken from the NOFO but Mark anything you want to touch on from the slide? Before we talk about additional response builders and characteristics to look for?

MARK CRENSHAW:

The way I read this is... You want your... I want my self advocate faculty member to be engaged in all of the ways that other faculty who work with LEND are. So I want them to be engaged in mentoring trainees from their specific discipline, I want them to work with the cohort, I want them to teach and mentor trainees from their discipline and outsider discipline. -- Outside their discipline. I want them to help us make connections to appropriate and important experiences for trainees.

The point of this being, I want the self advocate faculty member to be engaged in every aspect of the program, and I would not think about just limiting their influence on the program to just working with self advocates.

MOLLY TUCKER:

So these are some additional responsibilities that the self advocate faculty might be responsible for, assisting with trainee interviews, especially for self advocate trainees, attending all team meetings and planning sessions as we said, if possible attending courses in order to support the self advocate trainees during the classes themselves, or being able to preview or review content.

Participating in all the research and evaluation activities that you have associated with your program, and then kind of based on their availability, the opportunity to practice and participate in work groups and special interest groups at the AUCD level, or in your local community, that are disability oriented.

We actually have a question for all of you, so I'm going to ask this question to you... The self advocates see is a full-time paid position of the LEND?

MARK CRENSHAW:

I think the answer to that depends on how your LEND is structured. Our LEND does not have any faculty member that is on the project at 100% FTE. So in keeping with that structure and budget, our self advocate faculty member is not 100% on the LEND budget, he does have other work that he does, and he connects with other self advocacy activities locally and in our state.

He also is really interested in technology so he does a lot of work with technology. Around the center, and supporting LEND faculty in me to implement... To organize the technology related to our program.

So yeah, Laura the answer is, I think it would vary across LEND Programs, but it is not... Our faculty member commitment to LEND is not a 40 hour a week commitment.

MOLLY TUCKER:

But they are paid.

MARK CRENSHAW:

They are absolutely paid, they are on the budget.

MOLLY TUCKER:

Alright so we are going to ask you guys this question we would love for you to put your answers in the chart. What characteristics or traits do you look for in a self advocate faculty member? I see Megan you said in Oklahoma "the self advocates discipline faculty is part-time as are all the core faculty. Was go sound similar to ours.

-- That sounds similar to ours. Let's see, what characteristics to look for... "Willingness to educate trainees and share their experience." Thank you Caroline.

Anyone else? And again, feel free to come off mute as well, yes, "having a self-starter, self initiative."

[Us_Daune is Live]

Experienced leaders experiencing leadership it connected to the greater disability communities. Yes.

SPEAKER:

This is Gabby is really late so not doing well. I think first you have to believe in the program. Then you have to believe that others can gain from this and you have to believe in this. When I mean and I think this is also self-inflicted. We have to be able to help them that they are there for simplicity.

MILLY TUCKER:

Cathy you mentioned several things were going to talk about your so right about understanding the program and helping build people up and I think that makes so much sense to think you for sharing that.

SPEAKER:

You are welcome.

KEVIN SHAW:

Seal several people said from formal LEND training helps and is great and endorses it. From my perspective LEND is an interesting phenomenon and it helps to have people who understand the goals that you are trying to reach. Yes, Shelley your comments are right on. Patience, creativity. Able to engage in the process of making things universally designed. An ability to connect and has effective communication skills for sharing.

MILLY TUCKER:

We are going to go through some traits and characteristics that we think are important. In even touched upon several of these already so this is more of a summary of what you've said. The back of one of the things we said is a passion for advocating with them for people with disabilities at death to be able to support a mentor and other self advocates be well connected with the disability community and I'm sure that exact phrase was in the chat box. And again has prior experience or understanding of the LEND program.

I told Mark before that trying to explain my talk to people is hard so having somebody who understands what this is all about is really beneficial. I see the question in the chat box. Steve you asked a question. Do you mind answering that before we go to the next light? 2 questions as far as stipend how do you ensure that they receive benefits through Medicaid and Social Security are not cut New Jersey tends to be extremely strict and soon to change with the state bill. What modifications can be changed and made for advocates of difficult aspects of the reading writing or learning disability. Can you provide examples of modifications that were made?

MARK CRENSHAW:

That is great. With self advocates we have these challenges before. This is not the first time I'm having conversations with other training directors and LEND challenges related to your Medicaid and work requirements and benefits. I will say that we have? These are questions we ask when we are interviewing so we work really

hard to individualize our response to every training related to to what can happen given how much they are able to make.

And have actually had this conversations with folks who do benefits and navigation to make sure that the stipend is not going to put benefits at risk. So I would just say have those conversations with trainees and if you need to call an outside expertise, because I certainly when I began this position was not an expert on those issues. I have come to learn a lot about Clinton years of doing this. But for sure did not know, even when I didn't know from the beginning so drawn on expertise in your state and talk to the self advocate and/or their family related to what impact the stipend is going to have and if there are creative ways to compensate.

There are other options that need to be considered. I hope that helps and if other folks have any suggestions I am glad to hear those as well.

MILLY TUCKER:

I see in the chat was like some state has had success with the caps being lifted and with a lot of people mentioning the importance of the enabling account if your state has any readily available so those are 2 other options as well.

One person said what a day of direct payment is issued for support conference trainings and other educational training supporting of LEND.

MARK CRENSHAW:

We are certainly dirt done that. Where we have helped folks, as a part of their individualized leadership plan where we have supported them to attend self advocacy trainings where we have supported them to attend. Like the Aboriginal Education Council conference for instance. When they could not receive a direct payment.

MILLY TUCKER:

That's a great question and thank you for asking that. Some of the things we look for for self advocate faculty is the ability to think critically and provide impact that will strengthen the program and not just content for advocate training. Somebody who. Tradable showing there training with faculty and staff and able to discuss the transition from pediatric to adult care. The benefit against someone who is willing to share their story and be self reflective. Mark do you want to talk about why that 3rd bullet point is important?

MARK CRENSHAW:

Absolutely I think that it is important because there is so much of our content, because we have dedicated time to content related to challenges in the medical transition. So in addition to our family men touring experience in the ethnic experience to have somebody in the room that has navigated that transitioning personally or currently navigating some challenges related to it brings a level of reality to the conversation that is really important. I will say that we did not include this on the slide, the also I would add to that the experience of our self advocates and our self advocate faculty related to their school experience. The patterns are related to whether they were in special education and what the setting looks like or reflections on that can also be really powerful in the context of the conversation that we build.

MILLY TUCKER:

J you said it's very important to frame and treat the self advocate faculty as the same level of self-discipline or experts that we are and we 100% agree. That is why Louise said they are involved in all the same meetings and opportunities that are core faculty are. They are present and in some cases,? Feel free to talk about this, sometimes her self-efficacy faculty are more engaged than other people.

MARK CRENSHAW:

For sure. And I think that it is intentional on our part in some ways to make up the case. We do compensate the self advocate faculty at an appropriate level given the time they spent with LEND.

A part of it is because we want them in the room. We want them engaging with trainings. We want them helping teach the LEND sessions. We want them to reflect on their experience and asked encourage self advocate trainees to reflect on their experience. The other thing I will say about that there are times when the self advocate reflection on their experience is the most important perspective in the room.

In the context of that I definitely want to make sure that there's more than one self advocate perspective when that is the case. So having the self advocate faculty who is in the room to support self advocate trainees is really important at the moment swear that perspective needs to be amplified.

MILLY TUCKER:

I think that goes along with Christian common sense is not only standard for themselves but to be the voice for the self advocate that cannot speak up for themselves. Kind of like what you said sometimes her advocate faculty serves as a model for advocate trainees who maybe are not quite comfortable yet sharing their perspective on not sure how to process it and work it is so getting sitting next to somebody who models that is really important.

Steve, regarding modifications, we talked a lot about modifications in our curriculum during our first session with Universal Design for Learning and community and creating inclusive learning environments. A recording of that will be made available by a ECD but also if you have additional questions Mark and I will put our emails in the top box and happy to set up a time to talk to you further as well.

We would be happy to provide more information on that topic.

MARK CRENSHAW:

And just the short notes version of that is when our trainees engage with content whether they are self advocate or someone who is getting a PhD or Masters degree or community trainee, they have the option about how to engage with material. The back of some read, some listen, some have a conversation, and so that is a part of our commitment to Universal Design for Learning in a cross curriculum experience.

MILLY TUCKER:

Thank you for putting your contact information in the chat for us. We have 2 more

slides that we look forward when we come to faculty. Because as you guys have mentioned faculty is a crucial part of this. Whether it's supporting advocate trainees or helping to create a more inclusive program. Some other things we look forward is somebody not intimidated that may have advanced degrees is somebody who is not intimidating to other self advocates and is approachable and able to build rapport with individuals. Somebody understands are multiple ways for trainees to be successful this going back to artists our conversation about Universal Design for Learning so there's a lot of different ways in able to understand that.

And Mark you can talk about this but somebody who has experience navigating systems as both a and adult and family member and can provide the perspective as it relates to person and family centered care. And is there anything you want to add on this

MARK CRENSHAW:

I do not think so those are self-explanatory.

MILLY TUCKER:

This is the last when you put this in the chat box. Somebody who is a strong communicator and is not only able to articulate ideas but is also able to talk about and talk to multiple different audiences. Somebody was able to take that message and make it understandable for wide variety of audiences. Somebody who is able to engage in conflict resolution because sometimes conflict will happen. The progressive somebody who can mediate that somebody was a lifelong learner and is patient and self regulate. Somebody independent and willing to receive feedback. Marcus seen the checkbox that Mary said that experiences a family member in regarding in common navigating system can you explain what we mean by that?

MARK CRENSHAW:

Absolutely. Mary in the context of that I think what were getting at is that the self advocates exist in a context prior to coming to their experience as an advocate. They were a member of a family of some sort of diverse constellation so we are not talking about family members replacing the voice of self advocates were talking about the voice of that advocate have someone who is experienced as a member of the family.

Mark as the training director you obviously supervise heart advocate faculty. Can you talk about why the ones on the screen right now are really important to you from a supervision perspective?

MARK CRENSHAW:

I would say... If I were to make a list of the things I want from everyone I supervise, this would be the last. I want to have the same... I would not want to have a different list for myself advocate faculty member than I do for anybody else I supervise.

MOLLY TUCKER:

Alright. We are now going to transition to a conversation briefly about interdisciplinary training. So when you screen right now is an image of five circles, the first circle has one circle in the middle and it says interdisciplinary

--intra disciplinary, which means one discipline, for the purpose of this, perhaps self advocate within LEND, the next circle has lots of circles inside of it, sitting at a table, sitting in a circle of each other, and it is multidisciplinary, which is the ability for people to work together, to have their unique perspectives and work together to solve a problem.

Then you have cross disciplinary, that's our third circle, and that has circles together, that form the shape of a flower, and the purpose of cross disciplinary is the ability to take the perspective of another discipline, for example I am a social worker, but how can I take the perspective of someone who might be a school psychologist?

Being able to take their perspective in that situation. Then you have interdisciplinary, that is all of the circles on top of each other, making some of the Venn diagram. This is all about integrating knowledge from all those perspectives together, and the last one is all of those circles layered on top of each other to make one new circle. And that is transdisciplinary, moving past the idea that separate disciplines exist and how can we all come together to have one new intellectual framework?

The reason we bring this up is just as the picture depicts, we do not want our advocate trainees to be in a circle by themselves, we do not want them to be learning by themselves, we want them to be part of this interdisciplinary training, to see how all of the different programs work together, how the different disciplines work together, how the perspectives need to happen alongside each other to work towards a solution.

So we just wanted to do so to provide that because I think it is a really good visual of... Imagine if all of your other trainees are interdisciplinary and your advocates trainee is over here by themselves, that is not going to fulfill our requirement of being an inclusive training program, so we want to ensure this idea that everyone is layered together, and able to take multiple perspectives towards moving to our new goal.

So for us when we think about the self advocate discipline, and I cannot remember who said it in the chat box, but they should be treated like any other clinical or nonclinical discipline. They do not need to be treated in any other way. You want to make sure they are fully integrated into all aspects of your training program.

So one thing we want to highlight is there might be that concept of getting additional supplemental content through the supervision meetings with the self advocate faculty. But that does not need to be an additional curriculum necessarily. They're not necessarily learning a whole new set of skills in that conversation. That really might be to reinforce their learning, preview new material, talk about what they are experiencing, reflect on those content lessons they have experienced thus far in the program. And Markey said this already, but this conversation should focus on leadership, and what is next for the individual, be goal directed, where we going to go after this program?

The self advocate discipline is not necessarily its own curriculum, just another

perspective being brought to the larger conversation. Mark you want to add to that?

MARK CRENSHAW:

Yes I would just say that in terms of the content reinforcing, or reinforcing what is happening in the larger program, and the opportunity to preview content, often in my conversations with self advocates in LEND and also in Kirk's conversations one of the self advocates will share a story that is about how the content connects to their life or their experience, order advocacy, and sometimes the question in that supervision session is...

What we need to do to support you to tell the story will make it to class later today? Or later in the week? Because that is a really important perspective for your colleagues to hear. So just to say, from my perspective, in terms of what the opportunity to have those discipline specific meetings with the self advocate faculty does, it might obviously help the self advocate feel comfortable about what is about to happen. In terms of the preview.

But it also might help them think about how to share their perspective in a more powerful way.

MOLLY TUCKER:

Yeah. I often think back to universal design for learning, so we said those three principles are engagement, action and expression and representation. So by previewing the information, that is one where we are representing the content, to make the person feel more comfortable or have a better idea of what to expect, what kinds of questions might be appropriate to ask. When it comes to action and expression, Mark said this during our first session, but not everyone feels comfortable sharing their thoughts in the larger group, maybe they need more time to process or reflect on that, so being able to talk through that with the faculty member, might be an opportunity to decide, what did that really mean? What is something I need to learn more about? Is there additional questions that I might have?

Then from an engagement perspective, a lot of the time, those meetings can help poke the person into why this content is going to be important to them. One of the things that is going to be important for you guys, when you're thinking about your advocate faculty, if they need to build relationships with those trainees. The stronger the relationship, the better able they are going to be to say "we're going to talk this week about disability within the justice system. I know that personally you are interested in that topic, so what kinds of questions might you be interested in asking? Are the things you might be interested in knowing more about?"

It is the opportunity again to take those three components into those conversations without developing a brand-new curriculum, so I do not want you to feel like that's necessary, it is really about the idea of reinforcement. Mark, anything to add, look like you are about to say something.

MARK CRENSHAW:

No that was great.

MOLLY TUCKER:

So these are the four parts of most LEND programs, the didactic and coursework, the clinical experiences, community experiences and projects. Or research projects.

So for the didactics, I think we want to highlight this, and Mark will give examples for all four of these, how we make sure trainees are included. But your advocate trainee should be included in all aspects of your program. They should be present in your courses and should get to engage in clinical experience, they should be actively involved in community activities, and any sort of research projects whether it is individual or group research they should have the opportunity to engage in that as well.

Mark you want to talk about how we have integrated people into all of these and what we have seen people be able to do as a result?

MARK CRENSHAW:

Yeah, just in terms of integration, in today's didactics, -- into the didactics, we've talked about it a lot but providing a real-world perspective, about something that is being discussed, or being able to have conversations about how course content, didactic content, is stretching them to think in new ways. And helping them reflect on that in the context of the sessions. Just like all the other trainees do. When they asked questions, provide comments or feedback.

In terms of clinical experiences, when we first started, this was a little bit of... It spurred a lot of growth for me in terms of what the possibilities were. So having self advocate trainees go to interdisciplinary clinics, where children with autism, and other neurodevelopmental disabilities were receiving care, was often an opportunity for the self advocate to provide their own experience, and be in the room and say "I really understand what is going on I have had a similar experience. And here I am as an adult, or these are some of the things that my family was dealing with that your family might be dealing with" in those kind of things.

I think in terms of a number of our clinical sites, they really love to have self advocates be in the spaces, because it opened up opportunities for relationship building that might not have existed without our advocate trainees in the space. In terms of the community experiences, talked about our policy and advocacy related content. Giving folks opportunities to participate in going to the capital, and connecting with their policymakers. And other various things.

Sometimes we have a really great autism serving organization in our state, or in the metro Atlanta area, called spectrum autism support, and it really did just start out as family support. And it is engaged autistic self advocate supports over the years, and they began to expand their offerings, and a number of our trainees, post LEND, have gone on to be leaders and those advocate support groups.

In terms of research projects, we have always had self advocates as part of our participatory action research projects. The key with those projects is that trainees, every trainee gets to select the project they are going to work on. Because we think that is important for engagement and motivation. So self advocate trainees, are just the same. They get to select the project they work on, and have

opportunities to provide subject matter expertise in a number of cases, on those projects.

Molly is working with a small group of trainees right now, there is an autistic self advocate, who is in that research group, and it is clear that the perspective of the autistic self advocate, in many of the meetings, is the most valuable perspective that that group benefits from on a regular basis. And that group would be diminished if he was not in those conversations. So just thinking across those buckets of experience.

MOLLY TUCKER:

Mark, I was going to ask if you could talk about three other things, when you talk about choosing the projects, our LEND does not do individual research projects, we do what Mark says is called participatory action research where Mark spends time working, either with community-based organizations, or with other members of our (unknown term) and LEND team to bring trainees onto projects. As he said, I am working on a project right now about creating and curating resources for individuals with autism who identify as part of the LGBTQ plus community.

We have folks working on special healthcare needs projects, so when he says they select projects, we provide the options of the projects available, and they self select which one they are going to do. I know for a lot of you guys, you do more like individual projects, so wanted to make sure we clarified what ours looks like. But Mark, can you talk about why you think it is important that our advocate trainees participate in our family mentor program as well as our advocate mentor program?

MARK CRENSHAW:

Yeah, yeah. I think in terms of participating in the family mentor program, just having the perspective that not every family is like the family that they are a part of, and obviously one of the things we try to do in terms of the matches with those families is make sure that they are a family who has a diverse disability experience, so that when we talk about coalition across disability, opportunities to build Cross disability coalition, they begin to have a relationship, and no some stories related to a family with a diverse disability from their own, and challenges and opportunities for better systems navigation, better coordination, better sort of advocacy together.

Because they are a trainee who is autistic, and they are paired with the family who has a child with cerebral palsy or something like that.

MOLLY TUCKER:

That is actually what Darian was talking about in his video about the project that had been so meaningful, was he was paired with a family that had a son that in some cases has had dozens of seizures a day, and that is had a significant impact on him and his family, and he on multiple occasions throughout his LEND experience talked about how much that has shaped the way he thought about support for other people, because he had never been exposed to something like that himself. Mark you want to talk a little bit about advocacy mentors?

[Us_Daune is Live]

MARK CRENSHAW:

Talking about advocating experiences and working with an advocate who is on a leadership trajectory and in a number of ways to see what it looks like past LEND years in your time in LEND. Where they will utilize the connections that they are building and utilize this network to move forward in their advocacy journey.

MILLY TUCKER:

One thing I wanted to mention about our advocacy mentors is most of them are alumni of the my voice program or alumni of Georgia Georgia LEND. For those who maybe have not come through LEND it is also an opportunity for us to expose to them the curriculum and what LEND looks like to hopefully eliminate or at least eliminate their fears about the ideas of participating. So works for us from a recruitment strategy from introducing these advocates to be another opportunity they may be able to have in the future so that is something else that we do. I wanted to reach her comment is a long-term treatment includes advocate training and leadership placement similar to the research project. We also have a policy experience all trainings experience in the spring semester. So that sounds very similar to what we do and vary so much what other people are doing. Thank you for being here though.

A couple of more things about completing the LEND experience. And again some of this was brought up in your question and you've asked really thoughtful things that are relevant. So thank you. As is said generally they are asked to complete their training through a 12 month period but sometimes self advocate trainings may complete it in the course of 2 years. It's important to know if you have a self advocate training who's doing it over 2 years they can only count as a self advocate for one of those 2 years. You cannot double count them they may do work over the course of tuba can only be counted on one of them. Their statement could be distributed over 2 years instead of one and what we recommend and Marco would love for you to talk about this is if you cannot have a trainee participate in the 2nd year we recommend you talk to your project officer and go over that to make sure everybody understands the expectations and what that person will be doing or why they are continuing their training over the course of 2 years.

I can see you set yours up as a mentor.

MARK CRENSHAW:

Brian that is been common for us to do so thank you for raising that. As somebody from the program whose had to make this as a project officer I would say the project officer is there to provide guidance related to your intense of the LEND guidance itself. I thought they want to help you follow the guidance appropriately and give you ideas about strategies and may be about how other programs have done this.

So the other thing I will say is that the Novus also says that it begins this paragraph about completing 2 years talking about families and self advocates having the option to complete their training years and their 300 hours over 2 years. And then there's the option for trainees who are not families or members are self advocates to do that as well. And once again I would amplify to you to talk to your

project officer and help you figure these things out and they want to help you do what is best for your trainees and your program.

MILLY TUCKER:

Brian I see your hand is raised would you like to ask a question?

SPEAKER:

I just wanted to to share the intended audience for this is other LEND sites or as a potential trainees or both? With this series. It think there's 3 and this is the 3rd of 3 webinar series.

MILLY TUCKER:

This was really designed from one new LEND programs that were just funded so the lender would understand what the expectations are in advocate trainees. To give training programs more resources or ideas if they've not had advocate trainees in the past.

And again to help broaden the knowledge around advocate trainees across the network and be able to take in the collective information that all of us are able to share in these conversations today and in the past 2 weeks. Mark did you want to add to that? Chris? No, I think that is great. Brian what I would say is as I have learned things about how other programs navigate the stuff that is helpful to me. While this was a form originally for the newly funded LEND program to understand including self advocate trainings we realize that not all LEND programs have fixed or clean included self advocates. There is a requirement in that for 2021 to 2026 that they do that by the 3rd year of this cycle and that they have self advocate faculty in place as well. So we just wanted to have our partnership with Aboriginal Education Council D around this is which is help all of the programs be on the same page.

SPEAKER:

Got it. Knowing more from you edifying intended audience I just wanted to share and welcome the uncomfortable. If I'm talking to a person with a disability you know what I am talking about because everywhere you go you have to be the guinea pig. And then we choose how much distress tolerance we can handle on that day and time. But now I am talking to LEND sites growing program designers people who are like I'm the mentor? Or uncomfortable with that. If you can be open a bit about that process then you can identify with that training and that trainee can identify with you.

And hopefully with some patience and forgiveness you can work together to figure out how you are going forward. Many other sites are doing that. I invite you to check out the vast resources in a ECG rep network. Because when I'm aware of is called the specific Pacific West LEND self advocates lessons learned. I do not know if that was recorded or not are available but that particular one that I did not attend there are others. But again welcome the uncomfortable. It is able to be figured out and yes there will be frustrations and thank you for letting me share.

MILLY TUCKER:

You just reinforced for us that we are here to provide hopefully, some groundwork for people in some foundational understanding but I think you just brought up a great point. That Mark and I were talking from one perspective and we tried to

bring in other programs as well. But there's so many people in the network to reach out to do not feel like you're going about this alone. Student Susan you just said 30 years for the dance to remain so there's a lot of information to share and learn from so thank you for that Brian. It is important for this. Robin I saw that you just wrote in the chat box is there anything you want to come off of mute and say? I want to make sure I give you the opportunity.

SPEAKER:

Unfortunately this is great unfortunately I missed some of the trainees due to the death in the family but am happy to be here today. I was just thinking you in the chat box for grounding everything because you have a wealth of experience that your program and have thought of it so well and I appreciate how you have made it really clear and tied it because I think it will alleviate some confusion even amongst existing programs and I like how you gave examples of all of the different components of LEND because I think many programs struggle especially with the clinical component. So I think that that is an area where a lot of programs would benefit from some more technical assistance or one-on-one discussions so I appreciate you just for including all of that and thank you for this.

MILLY TUCKER:

For those of them who do not know you? Could you notice yourself.

SPEAKER:

Yes. I am one of the LEND a team lead here at the Bureau. I'm not sure if my colleagues are on. There's a team of 4 of us in on the team lead and I've been here for a while and of had the pleasure of working with Mark and Molly's program and many others. So thank you.

MILLY TUCKER:

And we appreciate your input and thank you for being here. So we will do our last section of our presentation and then we will be finished for today. If this last section is all about recruiting trainees. So we talked about what you should look for and what is important for your faculty but now to be how do we find them and how do we get the right people in the room. So we want to ask you guys that question how do you currently recruit self advocate trainees? If you would mind putting that in the chat box or come off of mute stop go ahead Brian.

SPEAKER:

The time proven test invested method for anything in somebody's been through it. And I can tell you 2 days ago at the privilege of meeting an individual who was individual who was referred to a site for consideration to be the self advocate trainee to apply but needed an introduction and a person who referred them to me was a lens fellow. That former trainee although is the person with the disability and a beautiful advocates went through as a public health fellow not the self advocate fellow. So talking with this person 2 days ago was this a couple of tracks and a couple of ways to enter. The thing is called latent and is ensconced in interdisciplinary healthcare training. But the short answer the time proven way is to stay in touch with your people after they graduate because they are the ones very likely he will send more people your way.

MILLY TUCKER:

Yes. I make fun of Mark because he knows what every person is doing all times after they leave. But it's been so effective. Not only for advocate training before all trainees. For him to stay connected. To hear about those referrals and recommendations that we've talked about last week where relationships play such an important part of this overall process.

I will make fun of him but he is the key of staying in touch with people. He may be the best person to stay in touch if anybody ever met. It is such an important part. You look for state disability networks. Stay in close secondary programs. I think McCafferty you discovered our next slide.

MARK CRENSHAW:

We are done with this now.(Laughter)

SPEAKER:

I look at that different advocacy groups. And I look at advocacy groups for soul which is self after you see leadership team. I will look at people I already know and understand what advocacy is then introduced them and introduce them to this kind of work.

MILLY TUCKER:

Cathy mentioned this idea of people who are already interested in this. And already a part of advocacy that goes back to this earlier and has that foundation of cognitive skills. The paragraph a lot of people do this for themselves like you see them doing it for themselves because because they want to get involved to make their own waves. But when you tell them about this you could do not a bigger level and you could get get further than leadership in it. It can be other people that get paid to do this. Did they ever see that to be paid to do this job. When they have a stipend or more they have an emphasis? But I was the only unpaid person in my group. And I was doing the same work they were. But I was the unpaid person in the room and everybody else was a paid person. So when you tell people that they can make a little money doing this that changes the whole experience for them.

MOLLY TUCKER:

You're right, it might be a motivator, or given extra incentive, but I think you also beautifully mentioned what Mark said through all three of our presentations, is this idea of moving from advocating to yourself to advocating for the larger community, so thank you for reinforcing that. Finding people who want to do that is a key part of this conversation, so thank you for reinforcing that. Mark, anything else in the chat box you want to highlight? I saw a lot come through.

MARK CRENSHAW:

I think Susan from Maine talks about reaching out to their self advocacy organizations. Talks about one specific, the director of their Speaking up for Us in Maine. It is a role model for individuals she supports, and she helps recruit self advocates, that is great.

The funny story I want to tell, is now I also have self advocates trainees who are recruiting other trainees to LEND because they have had a LEND experience, and they

are like "this really was important for me, and I think you should have the experience as well."

So not only are trainees without disabilities looking for self advocates on behalf of LEND, in Georgia now, but it is also going the other way, and so that is been amazing.

MOLLY TUCKER:
Go ahead Brian.

SPEAKER:
You go ahead please.

MOLLY TUCKER:
I was going to go to our slides and summarize whatever and just said so please feel free to add before.

SPEAKER:
I am just going to put some more wind under what Mark was just saying. When we welcome in as a site, except the funding or are granted or awarded, and then we are like, that was half a year ago, year and 1/2 ago, now we actually have to do the thing, I do not know how, I am trying... And to go into that space of uncomfortable. Embracing that, welcoming that figure it out together. Create this dynamic... And now I want to speak to the self advocate trainees especially, the more experienced ones, because Mark was just saying. Those ones are now being looked to, people are coming to them and saying how do we do this? We want to do this, what you guys did.

And it is rather a privilege, as mentioned earlier, when there is a stipend, when there's pain involved, people with disabilities have been historically undervalued, both monetary, as well as many other ways, and this is getting at the pioneering edge, the white water foaming edge of a wave, and so yes it is uncomfortable but it is definitely a wave, it is a movement, and as we can be a part of it, we can help it grow.

We can help the other people who are uncomfortable, and I have found, even medical directors, uncomfortable, how do we do this? And if you can just join the conversation and say "I don't know, let's try this or this." It is getting people with two giving people with disabilities to help our peers, and our peers become not only other people with disabilities, but also doctors, also program administrators, also technical assistance folks, AUCD folks, folks like Robin in the MCH, the project manager folks. They are like "we need you."

And boy, it is a great part of the human experience, when we can say "I need you." And you say "OK I guess I have something to offer, let me jump in."

MARK CRENSHAW:
And I want to build on something you said, in LEND our peers become fellow leaders. That is the other issue, the reason that people who do not have disabilities, nondisabled folks, are looking to self advocate trainees, is because they see in them the seeds and skills to lead. And they are drawn to... How did you get there?

How do I have a similar experience?

SPEAKER:

Ya. Hashtag do uncomfortable things, I am a performing artist, swag on stage, and all those nerves, whatever, and that is an essential part of being a human, how many of those things did we do because we were confident, walking in our stride, going in our flow because "I have got this, I have studied this." And how many other things do we do... It was either do it scared or don't do it. So do it scared.

MOLLY TUCKER:

Brian you are reminding me of a conversation I had with one of our self advocate trainees a couple weeks ago. He and I already knew each other, he went through several of our other programs in the past. And he was telling me, "I am not sure about this. I don't know if I am the right person to be in the room." He literally asked me if I made a mistake, and I told him "one, you have to wait more than two weeks (Laughs) And let it all sink in." But I also think it was important to talk to him about how all trainees feel uncomfortable at the beginning of LEND.

Because you do not know what this thing is, what you signed up for, or where it is going. But I think sometimes just explaining, as he said, all of us feel uncomfortable, it is not just something that one or two of us is experiencing, it is also helpful to say, there are a lot of differences that might be brought up in a conversation, but there is a lot of things keeping us together, that we have similar reasons for as well. It was helpful for him to hear, other people feel weird? Other people are still figuring this out?

And I said that when I did LEND there was times when I was six months in, and I would go to Mark's office to say can you explain why we did this thing? It is part of the process, but sometimes you have to explain that it is OK to feel uncomfortable.

SPEAKER:

It really is, and in healthcare we do the imposter syndrome may be more than some of the other fields. I know people who are extremely qualified, and they are going "who me? Are you sure?" And I am like "come on now."

MOLLY TUCKER:

It is so true. So I just want to summarize what you guys have already said, but again, as written in the chat box, build relationships with community organizations and nonprofits in your area. Pipeline programs if your state has them, whether it is something that your state itself is offering, or there are partners in the state, other advocates training programs. Includes a post secondary education programs. That was mentioned as well. Two of our trainees that we highlighted today, no excuse me three went through Inclusive Postsecondary Education Programs and we now have nine of those in our state, so there are more people that we can look to who might serve that role.

You guys talked about this, referrals from past trainees as well as other LEND or other UCEDD faculty, if they met someone at an event, they would love for us to meet with them... Mark you get lots of emails about "you need to talk to this person..."

MARK CRENSHAW:

Absolutely. And I want to say, the larger goal, so I have had the great fortune of being involved in the disability community here in Georgia for a number of years, more than 20, and early in my career I sort of noticed that I would go to meetings of coalitions, of issues specific disability coalitions, and it would be the same people.

Just having a different meeting talking about a different issue. And what I will say is, after 10 years of having LEND in our state, that is not the case anymore. So increasingly, state agencies, nonprofits, are not looking to the same handful of self advocates to be the voice about the disability experience.

And that for me is one of the most important things that have happened over 10 years, is that there is a diverse growing motivated group of emerging leaders who have disabilities, who are disabled, who are contributing to these conversations, in incredibly meaningful ways. So just to say, all of this, from my perspective, is about growing the pool of self advocate leaders, who have meaningful contributions to make to conversations that impact them and other people with disabilities and their communities.

MOLLY TUCKER:

Just some other examples, I think one of you put this in the chat box, attending advocacy events in your communities and meeting people that way. Making sure you are connected with your DD counsel, protection and advocacy office, enter independent living councils, as they will have potential recommendations first -- or staff that they are working with that might be a good fit. The importance of word-of-mouth, highlighting successes and trainee outcomes, and providing alumni testimonials.

We showed you guys our people of Georgia LEND for four of our reflections, and that really does those last two things. Mark, can you talk more about why you thought developing that site was helpful when it comes to recruitment and highlighting successes?

MARK CRENSHAW:

Yet, partly because I did not think, at that point in the history of LEND in Georgia, people actually knew what we were up to. Outside of folks at Georgia State, outside of... I wanted to increase the reach of the training program. And I wanted to do that by showcasing the voices of trainees.

And helping them to reflect on what they were learning in the moment. To say "this is what I am already gaining from this experience. And this is why I show up in the room, this is the difference it makes for me."

So that has been really important, and I cannot wait, in a post-COVID world, to get to take new photos of new sets of trainees, and continue that. Because if you go on that Facebook page, you will see that it has not been updated in a while, and COVID...

But I think it is been important, and for LEND programs, I share the link to that

when it gets updated with my project officer, because I think it is great for her to see what trainees are saying about the experience they are having with us.

MOLLY TUCKER:

When Mark and I were putting together this presentation, I was looking at the site obviously, looking at people's pictures and to get their testimonies to include, and I found my person from Georgia LEND, which is exactly 5 years ago, and also thought it was a cool opportunity to reflect on what is happened in those five years.

So I think also having this type of archives for trainees to go back and see where they... How they have learned, grown, how their lives have changed, is also kind of a cool thing to be able to offer to people. So again, I had not thought about what I had said in a really long time, and going back and reading it, and seeing where I ended up, was a nice moment of being like wow, look what I have been able to do as a result of this that I did not think was previously possible.

It is also a great way for trainees to reflect on their experiences, and be able to showcase that, and shared with other people so they can know what this program is that they are doing for that year, this is another way to advertise the larger LEND program as a whole. Not just for recruiting new trainees, but to be able to highlight for who you are, what you stand for and what is important to your program. Go ahead Brian...

SPEAKER:

I have said it before, I will say it again, make mistakes, do not be afraid. This is healthcare, we are very afraid to make mistakes. There is no way to do interdisciplinary disability centric healthcare training without making mistakes. And the self advocate training fellowship may be should be the first one, it is not. It came along later.

They got the developmental pediatricians going in the physical therapists going, all these other disciplines going first and this is an add-on. Make mistakes... Learn from them. Thanks.

MARK CRENSHAW:

Brian, that is a consistent question I ask every leader who attends our leadership seminar. Tell me about a time you made a mistake and what you learned. And even, for about the first about nine years of our program before they retired, we had the 16th Surgeon General of US, is a regular speaker at the end of the fall semester, and he would get my question about failure, because I think that is such an important question in terms of formation for leadership, so thanks for highlighting that. And absolutely, in 10+ years of doing this, we have filled a lot! And we have asked for feedback, and we have taken feedback, and we have changed the way we do things because of the feedback of our trainees, and our faculty, and especially of our self advocate trainees and family trainees, because they are the people who are closest to this experience.

So if what we are doing does not ring true for them, then we need to reevaluate what we are sharing. With all of our trainees.

[Us_Daune is Live]

>> I think we both said The Centre first session. The reason we started to do this is because we failed a couple of times and made mistakes. We were not meeting the needs of individuals and people reported that they felt like that had a more robust experience if they were able to access information in a different way. A lot of what we're sharing with you guys in the last week 3 weeks has been a result of feeling hot things and being thoughtful and thinking about it.

So yes Universal Design for Learning is what we talk about at the first session or one of the things we talked about. I think you are right Mark, a lot of this stuff is just about being willing to admit when you make mistakes and even more willing to address them and figure out what you can do better next time in bringing the right people into the conversation to help make that happen.

I want to give a summary. And then we did that. I did not click fast enough. Just as a summary. This is a very big picture summary today. Programs need to self advocate long-term and have a self advocate faculty member by year 3 and should be training in all aspects of the Lynch program. Looking to turn it over not to questions you guys have been great thus far about asking the chat box but if there's anything you want to come off of me and ask please let us know. Does anybody have any questions? Jackie is OK. Sheri my screen so we can come back to the group?

JACKIE CZYZIA:
Absolutely.

MILLY TUCKER:
Think you all this was a wonderful conversation and we appreciate your participation.

JACKIE CZYZIA:
I think you to Mark and Molly not just for today's trainee but for all 3 training sessions. I know I've receded some wonderful feedback from the programs across the country about how beneficial these are. I do know there's more to come in the spring.

I just wanted to say thank you and everyone for particular participating and your input. All of the recordings resources and links will be available on the iTech website within a week. We will also send an email out with all the information as well so you can refer back to it. I believe we already put Mark and Molly's email address in the chat but we can send it around again and finally if you have 5 minutes to fill out our evaluation survey. I believe Jeanette is already on top of that and put it in the chat box. So that concludes our training for today. We can stay on if you have individual questions for Michael Mark and Molly or other feedback we would be happy to keep the line open until 6. So thank you all.

MILLY TUCKER:
Thank you everyone.

SPEAKER:

Thank you for your leadership and willing to be seen and be guides.

MILLY TUCKER:
Right back at you.

MARK CRENSHAW:
It is wonderful to interact with you in the space Brian. So thank you so much.

MILLY TUCKER:
I want to echo something Mark said earlier we may have been the people that were introduced as the beginning of this as the trainers but we've learned so much for the last several weeks from all of you we been having a lot of conversations lately about things we've heard so thank you so much.

JACKIE CZYZIA:
Happy to stay on if there are continued questions

SPEAKER:
And alive in person version this is where you go get your play in your food maybe pour some schnapps. This recording has stopped.

MARK CRENSHAW:
If we were in person I could go get a glass of wine now.

JACKIE CZYZIA:
20 we will be in person again.

SPEAKER:
In your case maybe you just take that wine under your desk and that you can show it to us.

MARK CRENSHAW:
(Laughter)Alright let's do that.

MILLY TUCKER:
Marcus at the office today.(Laughter)Speak and I think you all. See you.

JACKIE CZYZIA:
Thank you so much. And I think our ASL and captioning folks you can head out to you, thank you for your service today we appreciate it.