

Exploring Experiences in NJLEND: A Panel Discussion

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CARRIE COFFIELD: I'm Carrie Coffield, Assistant Professor of Pediatrics at Rutgers Robert Wood Johnson Medical School. And at The Boggs Center, I direct our pre-service training program as well as serve as Training Director for the New Jersey Leadership Education and Neurodevelopmental Disabilities program, the NJLEND program. And it is this NJLEND program and that we are going to focus on and talk about in this episode.

And so, to get into describing what this LEND program is and what the experience of being in and going through a LEND program is like, I have invited five former NJLEND Fellows to talk about just that on today's episode.

So I'm going to ask them to very briefly introduce themselves. And then I will turn things over to Steve Gruzlovic, my co-host for this episode, to really facilitate this conversation, so Steve...

STEVE GRUZLOVIC: Hi. My name's Steve Gruzlovic. I was part of the 2021 class as the first Advocate Fellow in New Jersey.

DOMINIQUE REMINICK: Hello, everyone. My name is Dominique Reminick. And I'm one of the Psychology Fellows in our most recent cohort in the year 2021-2022.

GENEVIEVE KUMAPLEY: My name is Genevieve Kumapley. And I was a Fellow in the 2018-2019 year.

COREY SHERLOCK: My name is Corey Sherlock and I was a Nursing Fellow during the 2018 calendar year.

DEEPA SRINIVASAVARADAN: Hello, everyone. I'm Deepa Srinivasavaradan. I was a Family Fellow of the first New Jersey LEND cohort in 2016-2017.

CARRIE COFFIELD: So thank you all for being here. And Steve, why don't you go ahead and kick us off with the first question.

STEVE GRUZLOVIC: So I think the reason why everybody's here and why everybody is listening, what is LEND? How would you describe LEND? What's it all about?

COREY SHERLOCK: So for me, LEND was an opportunity to learn alongside and from people in other disciplines and just hear different experiences, different perspectives in the field.

GENEVIEVE KUMAPLEY: As a Family Fellow, I was privileged to work with leaders, which is part of what LEND is, is leadership development, and education, and training. And so you put wonderful, brilliant people in a room, including families and caregivers. And we're able to share experiences and listen to experts to guide and lead the way, so just an amazing experience all together.

DEEPA SRINIVASAVARADAN: LEND training is all about the interdisciplinary interaction with professionals and other Family Fellows. It really gave me the opportunity to learn from professionals about how they are practicing family-centered and culturally competent care, and also share my experience as a Family Fellow to support them in providing that family-centered care.

DOMINIQUE REMINICK: So for me, LEND was a really unique training opportunity and something that I didn't necessarily have access to in my psychology doctoral program. Parts of classes or practicum here and there would have some of the experiences that I had in LEND.

But LEND was really just really devoted to having these didactic presentations, experiential activities, these conversations, discussions, and activities that were really focused on learning knowledge-building skills to support people with neurodevelopmental disabilities and their families. And really offered kind of a unique perspective, as other people said, it's interdisciplinary. So working with all of these different disciplines to gain knowledge of how to best support this population and also getting those perspectives from the people themselves, right?

The self and family advocates was just so crucial to my training. And I think this really helps me to be a more effective clinician and not only kind of in that clinical sense, but really helping me to build some of those leadership skills. It's leadership education so I can have more positive impacts and kind of greater-- to be able to more greatly affect change for this population. So it was a wonderful addition to the my psychology training.

STEVE GRUZLOVIC: Great. And going through this, what did you think or what was your preconceived notions that you had before you started? And did anybody have any notions of what it was, when they started the program? Because I got to be honest, I was a little bit-- I was a little bit intimidated just because I read the application and I saw that it was a little academic heavy. And I personally don't have a master's degree. I have a bachelor's. And I guess you could say I have a master's through life. So that was slightly intimidating.

But once I started going and going through the process, I realized that it's really not that intimidating. And people are really there to learn. People are really there to help each other and to work together.

DEEPA SRINIVASAVARADAN: I agree with you, Steve. I felt the same way because it said graduate-level training. But I had actually heard about LEND program in other states through other colleagues that I have interacted with. And they have always spoken high of the LEND program in their state. And at that point, we did not have a LEND program in New Jersey. And I was wondering, why don't we have one?

And when I reached out and asked one of my coworkers, or actually the executive director of my organization, she actually mentioned to me that Boggs Center was advocating for the LEND program in New Jersey and so just keep an eye out for the information. And then I started becoming very curious about what advocacy efforts were going on and started becoming involved. And as soon as I heard that we were funded to have the LEND program, I couldn't just stop myself from reading through the application and going through the application process.

So that was my idea about LEND before I participated in the program. And then when I participated, I was so excited to see that LEND was everything that I had heard about in other states. And I was so glad to have had the opportunity to participate.

COREY SHERLOCK: I had also heard about LEND in another state when I was living in Boston. And I had heard about it and was kind of attracted to the idea of just being, kind of what Genevieve explained, like in a room full of other people with passion and interest in the field. So I was really excited when it was in New Jersey, and it corresponded with my training. I don't know if I knew what to expect with the program, but I was excited to be surrounded by people with similar interest and passion.

DOMINIQUE REMINICK: Yeah. I had a similar experience. I had heard about the program beforehand, not in another state, but from a colleague of mine in my program, the upper cohort year that had already went through LEND and had some really wonderful things to say about it. So I came into this knowing that LEND would be great.

So I knew it would be great. But I wasn't prepared for how just awesome and phenomenal the program was. So that really took me aback, just the amazing content from the didactic sessions, the beautiful discussions and conversations we had and that interdisciplinary nature, the fabulous facilitators and faculty that we had. So shout out to Carrie, who's here with us, but also Dr. Deborah Spitalnik.

So really, very, very quickly, LEND became the best part of my week. And I had a pretty-- I had a pretty full plate. You know, I was in my fourth year of my doctoral program. So I had classes I'm taking. I'm teaching. I had externship, applying for internship. Do I have time for this? And this was the thing I was glad to wake up early on those Friday mornings to come to LEND, because it was just such a just transformative experience for my education and training.

GENEVIEVE KUMAPLEY: I could add to that a little bit. I didn't know anything about LEND. I stumbled upon it because I participated in a Partners in Policymaking program. And with Partners, there was a requirement to do a speech.

And I was talking about-- I think I themed it at that time Moments about Medicaid or Moments on Medicaid, because I was really impacted by the fact that Medicaid dollars is really responsible for providing supports and services for families like me. And we're already on that journey. So at that graduation is when I heard about NJLEND. And I was approached about it. And I thought about the

commitment. And I'm like, no way. This is like a lot. But there's a part of me that loves challenges. And I said, well, why not?

So I can't imagine if I hadn't taken that opportunity to participate in this program. It was life-changing. And you never realized how a decision, a singular decision at a point in life can have some huge impact on the trajectory in which your pathway is.

One of the presenters at the program, Stephanie Pratico, her program has now become a point in my personal family journey in helping us transition to adulthood. If I did not meet her there, hear about her program, our family would not have had the tools and the resources to transition successfully. So something that turned out to be we're getting together to learn from each other, me share my experiences, translated into a lifelong pathway for hope and all the other parts that's necessary for growth.

STEVE GRUZLOVIC: After you participated, how did your original viewpoint change? Were you were you not as nervous? Did you understand everything better?

GENEVIEVE KUMAPLEY: I will add that the corresponding responsibility of what I had learned is what I felt necessary for the next generation and the people I would share with. So I walked in selfishly thinking I'm going to gain information that will help my family, which it has. I just shared that.

But more importantly, out of this experience, going to Capitol Hill, visiting with politicians and policymakers, and standing there as a voice for the voiceless has been an amazing and awesome responsibility at the same time.

So my viewpoint of, oh, my goodness. This may be a lot of work academically has now translated into there are people's lives dependent on when I share my story and with the practitioners who hear the stories, who would now be better able to provide our family-centered care. So my perspective completely changed as a result of this experience.

DOMINIQUE REMINICK: Yeah. I would echo that sentiment, Genevieve. It's funny. Steve said something earlier about being intimidated by this being an academic program not having a master's degree. But Steve, you're one of the people in the cohort with me that I learned the most from.

Just hearing you share your experiences really changed my perspectives as a clinician, as a future psychologist. Really hearing about your lived experiences and trying to navigate these systems that we have in place that aren't necessarily designed in a way to be truly supportive to people with disabilities.

And I think that the unique thing for me about LEND is that it's designed in such a way that I was really able to hear you, the things that you said, Steve.

Because oftentimes, when I work with folks that kind of wear that hat of the clinician, and the therapist, and the client, clinician, and the patient-- but here, we were in fellowship together.

STEVE GRUZLOVIC: Yeah.

DOMINIQUE REMINICK: We're peers. We're colleagues. So I was able to kind of put that hat off, put my fellowship hat on, and really hear you in a different way, you and the family advocate that we had, the other people that came in to present about their personal experiences navigating these systems. And it was just-- that was really transformative to me, to be able to be in this environment, this context that was different for me. So I could truly hear and understand, have more empathy, have more compassion understanding their experience, and be able to bring that with me.

STEVE GRUZLOVIC: And one of the beautiful things about LEND is that that still continues today. We still reach out to a lot of members of our cohort and other cohorts. And I think that network is important. The next thing we wanted to talk about was 300 hours. There's a thing on the application that says 300 hours. Is that really the case? And how did you guys find that?

COREY SHERLOCK: I think the variety of the different experiences in the 300 hours is really cool. There's no other program or course I've taken that has been research, and projects, a trip to DC, poster presentations, and just getting to connect with other people. So I think 300 hours sounds like a lot, but the variety and the interesting experiences you get in that 300 hours is really unique.

DOMINIQUE REMINICK: Going into it, 300 hours to sound like a lot. But once you're at the end of it, you're like, I wish there were 300 more. Like even being here just chatting with all of you right now, it's making me miss LEND. I want to come back. Can I do it again? But in all honesty, I didn't really count the hours. But it definitely seemed doable.

I think it really just depends on each person's individual experience. I think there was that leadership development project that we had. And for me, I just used-- I was able to fortunately use my dissertation work that I had already started. So whenever I kind of continued working on my dissertation, that was also my LEND project. So the time kind of just flew by for me. And it was really easy to integrate with my other work.

DEEPA SRINIVASAVARADAN: I agree with you, Dominique. I think I didn't count the hours either. And I, honestly, between all the different experiences that we were able to get, it was just really so much fun and a lot of learning that just didn't realize that all that time went by.

And like you said, I'm missing LEND, too, and ready to go back on Fridays to LEND class, and be able to have that opportunity to interact with like-minded people.

And also, the other piece is that as I was going through LEND, I felt that it was fueling my passion. It was giving me more of a perspective on the work that I was doing.

So whenever I had to do something, or support a family, or whatever the case may be, or talk to a professional, I would always say, OK, let me put on my LEND hat, and think through the lenses of a

LEND Fellow, and see what needs to be done or what needs to be said. So when I was doing all of that, I really didn't look at the time or the effort that I had to put into that because it was so rewarding.

GENEVIEVE KUMAPLEY: I would echo that, Deepa, as you were just saying that putting on the LEND hat. So my background is a pharmacist. So in this class with the cohort, I had to wear two hats at the same time, oftentimes, the hat of the family discipline who is walking the journey and then also the hat of the practitioner. Because I understood from the perspectives of the practitioner some of the challenges they have and the lens.

So I found myself in a very unique position of learning from both sides and then applying that, even in my everyday work now. And 300 hours, I looked at it more of the months. I didn't count the hours. I counted how many months am I going to do this for and then trying to figure out how I was going to make it work,].

You know, my daytime job. I have a daytime job. So how was I going to convince my employer to give me time off? And honestly, I walked into my boss' office. And I said, I have an opportunity of a lifetime to learn whatever I can working alongside with professionals that will best help my loved one. I will work extra, and I will go in the morning. I'll come to work. I will work around it. I will do whatever I can to make sure my workload doesn't suffer, but I need this.

And when I said it like that, they made accommodations. So hopefully somebody's hearing this conversation. And you're thinking, well, I'm working. How am I going to make it work? You never know unless you go ask. Because the way I look at it, it was respite.

It was respite because I came into a place where I can share. It was like therapeutic. And it was respite because I was learning so much without the pressure. And I was with people who understood. So the cohort became like a family. And that's why I say it's a point in life that you look back and you're like, I am so glad I made that decision to participate, because it changed our lives, period. And you need that sometimes.

COREY SHERLOCK: I totally agree with you that doing these and any of the alumni events, I'm always like, oh. I'd go back to LEND in a heartbeat. I'd do 300 more hours easily. It's definitely therapeutic even still when we all get together.

STEVE GRUZLOVIC: So I just want to go around the room and ask, what was the best part of LEND? And then, also, what was the greatest challenge that you faced when you were in LEND? I'll go first, I guess.

The best part of LEND for me was the connections that I made and the knowledge that I gained from the other disciplines.

Some of the challenges for me were the differences of opinion at times. But I guess it's good to have discussions. So I wouldn't really consider that a challenge. But that would probably the most challenging part, was the discussions. Because it really makes you expand your mind.

DOMINIQUE REMINICK: Yeah, I agree with you, Steve. I think one of the best parts of LEND really is the connections that you make. So much wonderful knowledge, the skills you build, you become more of a leader. But really, it's those connections, those relationships you build both professional and personal.

I'm thinking of one of the kind of advocacy experiences that we had. It was some sort of webinar that I had attended. And one of the folks there was from the Office of Resilience in New Jersey. And we just kind of started chatting in the chat on the webinar, and then actually connected afterwards, and kind of discussed future projects that way. So kind of building professional connections was something that was really amazing for me in that moment.

And also, the personal connections, the friendships, like with you, Steve. I think we're supposed to maybe get dinner tomorrow or one of these days.

STEVE GRUZLOVIC: Yeah.

DOMINIQUE REMINICK: So yeah, so there's, yeah, that too.

STEVE GRUZLOVIC: Yeah, and they last for a lifetime. It's not just short-term connections. There's people that have done this program as far back as two or three years ago that I still call and talk to them, which is great.

DOMINIQUE REMINICK: And I would say one of the things that was difficult, kind of the challenges for LEND, one of them might be those self-assessments that we had to do at the beginning, which were really long, a little cumbersome. But I think you also helped with that, Steve. I think you've revamped some of that assessment process.

STEVE GRUZLOVIC: Yeah. I made them more accessible for everyone, disability or not.

[LAUGHS]

DOMINIQUE REMINICK: Exactly, a universal design, right? I think it's very useful here.

[LAUGHS]

Even just generally, that self critique aspect, kind of looking at yourself and thinking about what are my skills? What are my experiences related to leadership? You know, where am I? Where do I want to be? Where am I? How do I get there?

So that kind of self-reflection and even just looking at myself in these contexts and having these discussions and conversations as a person that, for myself, that doesn't identify as having a disability.

And really just kind of looking at my perceptions, and my assumptions, and making sure I'm kind of having that cultural humility, if you will. And that can always be difficult and challenging at times, but so useful and so important.

DEEPA SRINIVASAVARADAN: It was not one, but many favorite things about LEND. Some of my favorite memories are related to our trip to Washington DC for the Disability Policy Seminar and going on those Hill visits to talk with representatives about, I think at that point it was all about Medicaid. And it really meant a lot.

And as Genevieve said, it was all about families and being the voice of so many other families. So it really made a difference for me. And in addition, some of the other favorite parts about LEND was the thorough didactic sessions, the self-reflection that we did often about what leadership meant to us, working together on the LEND crest. So all of those are just unforgettable memories of LEND.

And the challenging part, I would say, is all about time management, which I always struggle with. Because as I said, I didn't count the number of hours. And every single piece of information that would come through my inbox, I would be clicking on the link to read it.

So I know there was additional stuff that I was reading, which took me beyond, way over beyond the 300 hours. And as much as I loved doing that, I also struggled with time management. Because I was also working full-time and trying to take care of my son who had just transitioned to college.

And so it was not easy. So that was a personal challenge I had. But eventually, it all worked out. And obviously, LEND was so good. And I have so many favorite memories. So obviously, it has been life-changing. And the ripple effect of having been through LEND is just continuing even to this day.

COREY SHERLOCK: The connections were definitely the best part for me as well. I'm just thinking of a few times I've called someone from LEND for resources or for a family perspective of like how do you give-- when the pandemic first started-- how do you give a diagnosis over a video screen? Or what would you want to hear as a family when everything is virtual?

Or calling to get extra resources for a family in need. And I think that's really neat that I have that opportunity to give families. And I have those networking opportunities and just people to learn from. So definitely the connections were helpful and continue to be really helpful for three years later.

GENEVIEVE KUMAPLEY: And like Corey said, and also Deepa said, and Dominique, the connections is a big part of it. Like I said, it was like a family. And we had differences of opinion, yes. Sometimes it was a little strong. But I think it was done respectfully. Because in this field there are diversity of ideas and thoughts.

And it's because it's still an emerging science, there are a lot that we don't know. And so oftentimes, people come in with some presumptions. And even the presenters may have their own lens and biases.

And so as Family Fellows who are walking the journey, oftentimes we will have to say, wait, wait a minute. It can't be that black and white.

So having the opportunity to share our viewpoints and be receptive, people being receptive to that was very helpful. I loved the Hill visit. We bonded. We had an opportunity to go on these visit and share what we've learned up to that point. And for me, it was part of the CARES Act. And that was huge, being able to share my personal experience with that, and with the policymakers, and eventually passed, so yay, and knowing that we were a part of history in that way.

I struggled a little bit in concluding on the project I was going to work on. But in the end, the project turned out well because I'm actually... refer to it.

I looked at what families perceptions, and knowledge of services that are available to them, and some of their concerns and issues that they have. And that's helped me to design activities for the families that I interact with. So trying to land on a particular topic to do that will be meaningful, that process was uncomfortable.

But I had help from my faculty mentor, Amy Kratchman and, of course, Carrie, and everybody else in the class. So we were all in it together. And picking something, like Dominique said, working on something that was meaningful, that you cared about. So while it may seem academic in nature, it really allowed you the platform or the opportunity to really work on something. Because you know there's a deadline. That's a due date. So you have to make it happen. Otherwise, one of those things like, yeah, when I have time, one day I'll do it. But in this environment, you were able to get it done.

And so I love many, many, many of the topics that we had. And the reflections that we had after those topics, really, really was impactful.

STEVE GRUZLOVIC: So what's everybody's hopes for LEND in the future? I hope that we have more disciplines participating because disability affects everyone in every realm of life. So I hope that we get many, many more disciplines.

I know this year coming, we're going to have dental students for the first time, which is going to be amazing. But I hope that we get even more disciplines.

And I'd like to see some disciplines that are outside of the medical or science field too. That would be nice, like architecture, or business, web development. We have an Advocate Fellow who writes for a local newspaper, which is pretty awesome. You don't necessarily have to be a part of a science or medical field to participate in LEND. It's for everyone. We want to make it inclusive for all.

DOMINIQUE REMINICK: Yeah. Maybe more folks in policy and government would be a good addition.

GENEVIEVE KUMAPLEY: Interesting, Steve, that you said that. It definitely broke the mold. Because when you first-- the first question was, what other discipline? Of course, naturally, being selfish, I'm like, yeah, we should have pharmacy.

But as soon as you said what you said, I'm like wouldn't it be cool to have engineers. Because if you think about the world of creation and innovation, that lens of being able to help individuals of all spectrum, all abilities, all challenges, and from the creative mind understanding the needs, will fuel that creativity.

And so you just hit on something so pivotal, that the focus is always on the folks that we have immediate contact with, which is the science field. But there's a whole host of folks outside of that who are needed to be able to help us to really better provide supports and services.

STEVE GRUZLOVIC: Disability is considered one of the five largest minority groups around the world and in America as well. I've learned through time you can become disabled, unfortunately, at any point. So it's important that when somebody acquires a disability that we have a network of support around them. And I think there's some crucial elements of LEND that can help with that.

DOMINIQUE REMINICK: Yeah. So that mini conversation we had now, where Steve just comes in and drops a truth bomb. And everyone's like, wow, that was amazing. That was my whole experience in LEND was just learning from Steve. Just everything that came out of his mouth was brilliant. So yeah. It's true.

STEVE GRUZLOVIC: Now, now, I'm not perfect. I'm not perfect. I don't represent all disabilities. I just try to share my experience.

DEEPA SRINIVASAVARADAN: And that's what we need, Steve. I think I'm just excited that I got to meet you and learn from you today. So I'm still as excited as I was when LEND was funded for our state, and we had our first cohort. And I know the first one or two cohorts we didn't have self-advocates. And then that was something that we were constantly talking about.

And I see that you have been able to participate as a Self-advocate Fellow. So I see that the program is growing and making all the needed changes and improvements as they are moving along. So I'm just still excited for LEND and so proud of where it has come now.

DOMINIQUE REMINICK: Yeah. And I think another fantastic thing that you said, Steve, was about having-- about not kind of representing all people with disabilities. And I think that's really important to consider in terms of maybe future directions for LEND. So including not just additional disciplines, but having not just one Self-advocate or Family Fellow, but having a few.

I think kind of having those perspectives, those different perspectives from everyone's unique experiences, disabilities or families with disabilities, but also to create those connections. I know the other Psychology Fellow, for example, we checked in about internship stuff. She connected me to someone

who works at the internship I'm going to start. So having those connections within your discipline might be useful for the Advocate Fellow. So I think that could be a good addition.

STEVE GRUZLOVIC: Yeah. And I think that about wraps up what we have to talk about.

CARRIE COFFIELD: Well, I want to thank our wonderful panel of former LEND Fellows. Steve, thank you as always for being a wonderful co-host and for, I think, asking the important questions. Hopefully, our listeners have a clear sense of what a LEND program is, and what the benefits are, what the commitment looks like.

If our listeners are interested in learning more about the national network of LEND programs, they can visit the Association of University Center website at aucd.org.

As well, if you're interested in learning more about the NJLEND program, we invite you to visit The Boggs Center's website and the NJLEND page.

So again, thank you to our wonderful panelists. It has been a privilege to spend this time with you, but to have been through LEND with each and every one of you. And I continue to learn with and from all of you. And it's a real privilege, so thank you.