**2024 KT Online Conference**

**HANDS Autism Engagement Network: An Evolution to Best Elevate and Learn from First-Person Voices and Lived Experiences**

*Presenters:*
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Transcript for audio/video file on YouTube:
https://youtu.be/tmafhz62vTE

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| Tiffany Neal: | To start my name is Tiffany Neal and I identify as a white or Caucasian female. I have shoulder-length dark brown hair and I'm wearing a gray sweater. Lexi, would you like to introduce yourself? |
| Lexi Westerfield: | Hi, I'm Lexi Westerfield. I identify as white or Caucasian. I have short brown hair, glasses that I'm blind myself so I don't know what color they are I just know they have tinted lenses, and I'm wearing a pink hoodie. |
| Tiffany Neal: | Thanks Lexi. Ryan, would you like to introduce yourself? |
| Ryan Steiner: | I'm Ryan Steiner, I clearly have trouble finding the mute button. I'm an autistic self-advocate and I'm glad to be here sharing today. |
| Tiffany Neal: | Thanks Ryan. Amy, would you like to go next? |
| Amy Shamanov: | Sure. I'm Amy Shamanov. I identify as white or Caucasian. I'm non-binary, my pronouns are they and she. I have long shoulder length dark brown hair, blue eyes, I'm wearing glasses and a pink flannel with a black T-shirt and I'm an autistic self-advocate and a professional in higher education. |
| Tiffany Neal: | Thanks Amy. Kristan, Mounika or Julie would you guys like to introduce? |
| Kristan Sievers-Coffer: | I'll go next, I'm Kristan Sievers-Coffer. I'm a white woman with glasses and long brown and gray hair with a yellow sweater. |
| Julie Smith: | I'll go, I'm Julie Smith. I'm a white woman. I have short brown hair, I wear glasses and I think that's all. Thanks |
| Tiffany Neal: | Mounika? Okay, so as we go through, we're going to bounce |

Kathleen Murphy:   I'm going to pipe in here a little bit, Sorry Tiffany. So you do have a lot of voices for people especially who weren't seeing to track. So if when it's whoever's turn to present, if they could just remind them, the audience, oh hi, I'm whoever, and I'm coming in from this perspective like I'm a practitioner or I'm an academic or something so they can kind of frame what you're saying. I think it'll help the audience to move from speaker to speaker. Thank you so much.

Tiffany Neal:   Yeah, thank you for that tip Kathleen. We're all going to pass back and forth, so that's why I thought the intro at the start, but I love that segue next. So, we are going to share about our autism engagement network and really the focus of the work that we do as part of our autism engagement network is really facilitating the elevation and opportunity to learn from those that have lived experience and really centering all of our efforts around first person voices. Next slide. First I'll start off with an overview of our center. Our center is an interdisciplinary training and resource center that has been around for about 20 years at this point in time. We do operate as an auxiliary or small business within the Indiana University School of Medicine. We have a QR code there and can drop in chat a link to learn more about us for those of you that are interested.

But ultimately our center operates or really upholds the mission and vision of Indiana University School of Medicine and Indiana University Health in terms of really focusing in on providing outreach, education, and training to build capacity or to best support those with lived experience and based in helping improve outcomes for those individuals with autism and related disabilities. Most of our team is comprised of and we deliver clinical services, so everything we train we also do in practice and then we serve as researchers or focus on research innovation and really looking at and working to understand the needs, barriers, facilitators, and how to best support systems and cross system discussion and bridging to ultimately improve or build bridges of information, resources, and collaboration so that if someone is able to go within a medical setting or a school setting or another setting that there should be a consistent language and that we're all working together towards improved outcome. Ultimately, we're working to increase local capacity and facilitating implementation of evidence-based practices through the development of regional community networks and communities of practice as we'll talk through today. Next slide.

Some of the standards that we work to uphold across all of our trainings is that we do have a comprehensive training model that's reflected there with the crimson and blue pentagon that is meant to kind of bring together all of the research around single strategy interventions that really work and focus across the lifespan. With that model, One thing that we have seen across the 20 years of implementation is that it is both responsive and complimentary to a number of cultural considerations, unique living situations, and ultimately is able to be tailored with consistency and fidelity to help systems adopt the model and implement the strategies to really improve acceptability as Mounika will share, in changing attitudes and beliefs and helping integrate those practices within very deep systems and ultimately to penetrate across procedures and systems. We work to make that accessible across a range of options, as you can see by that

green diagram there on the right that shows that we're working to really make sure at each level of service that we have a common language and a common understanding as well as training accessible to that level. But ultimately we're all getting on the same page vertically and understanding the core principles of really working to establish based standards and improve outcomes for those with lived experience. So as I mentioned here, we're working to meet people where they're at and improved sustained outcomes through agencies that seek out our trainings and consultation. Next slide.

You can see here, I know it's a very busy slide, but this has been very systematically developed over 20 years. So again, a path is very different from a straight trajectory. So one thing, as you'll hear from our panelists and really the programs that we're going to share about in this presentation, is that we have been very sensitive to the needs of our state, the needs of those that we're here to serve, and really responsive to seeking out additional opportunities for sustainability and expansion of programs like this that we see are having a very positive impact and improving outcomes for those with lived experience. Next slide.

So those that are represented here, next slide. We did describe in our overall partnership, so again, I don't want to take up time in going through as was mentioned, we'll introduce ourselves as we're going through, but we really did work as you can see in the coloring to make sure that we had a research or academic side, but everything that we do is very co-developed or very community informed in development and have worked to and really have the pleasure to work with a number of the advocates that are here on the call and that are depicted by their identified roles. Next slide.

So as an overview of the Autism Engagement Network, this is built on the literature related to mechanisms of change. So we've all been involved in a number of outlets where maybe you saw some positive outcomes, but if there was not that research and that data behind it, the sustainability or infrastructure for change with communities and persons at the core or at the fore is lost in the way. The field of implementation science is focused on really looking at how this change can systematically occur. We know from the literature surrounding the collective impact model that having a backbone core organization that is able to, as you see by the facilitator, navigate the research, have awareness or facilitation capacities to enable systems change, but always has a lens on consumer benefits and really who we're here to serve in terms of the individuals with lived experience is really central to being able to kind of enact this mechanism.

The agents with which we enact that are what we're going to talk about most heartedly within this presentation. One is the IIACC or Indiana Interagency Autism Coordinating Council, which enables us to have an influence at a policy, funding, and state level. And then the local level is what we call our Local Community Cadres, and Julie Smith will speak about that in a moment, and that really enables that regional voice. What those agents do is then represented in the means. So having these bodies at the state and community level then allow us to provide directed activities as means or activities that hit at that level that ultimately

prepare readiness. So, when we think about innovation, specific capacity, general capacity, and motivation, we're able to work across all of those levels. Again, with the eye always on the parents, caregivers, and individuals that we're here to serve. Next slide.

Within our network, as I described, within the mechanism of change, each of these are overseen or supported in different means, but what we wanted to really depict here is that there are a range of stakeholder groups, agents that we're doing, but at the core our members, that include individuals with autism, family members, caregivers and other professionals that are supporting those individuals. Next slide. One piece that was a huge effort with us with the IIACC and LCCs or the broader Autism Engagement Network is looking at how we can best meet individuals such as Ryan, Amy, and Lexi and understanding their perspective or making sure that when we are in a research or a policy sphere that we're best reflecting them in the data that's being collected and meeting 'em where they or in a means that is best for them to tell their story or to share their experience. So really looking at empowerment and participatory citizenship within these methods. So these are all, when you look at the literature mechanisms to provide first person research, I would say they're scantily used in a lot of research and we've really taken time to do a lot of interviews to follow up with focus groups to allow chances to share stories through narratives and could always do better, but wanted to share some of what that sample looks like in the research world. Next slide.

Some of the annual focus areas within our IIACC, as they'll suggest within the panel. Again, we do charting the life course as a trajectory to make sure that we're listening to those that we're serving and part of what they wanted to hear at the state level is depicted here in terms of focus areas. They wanted to hear more stories of innovation, success, and lived experience, have a capacity to develop or provide just in time or real-time input, and really to foster increased engagement across all levels, as well as hear about lessons learned so that we're not repeating those same pathways or trajectories. So providing ways that individuals can engage in a unique platform, but very centered on what our individuals that we're here to serve are interested in. Next slide.

So next is the IIACC and LCC pieces. Next slide. For IIACC, one of the pieces that we have depicted here is that we have facilitated the IIACC for the last 10 years. Our work is very centered on eight goal areas. These do align with our state's comprehensive plan for individuals with autism spectrum disorder, and you can see here at the center is continuing support across the lifespan and really respect for and access to diverse services as well as equitable access and cultural responsivity. Satisfaction is continually high in terms of meeting engagement and opportunities to engage. And you can see we work to make sure there's a diverse population represented and increasing, making sure that we have increased representation of individuals with lived experience. Next slide. Julie?

| Julie Smith: | I'm right here. Hey everybody, this is Julie Smith again, just to reintroduce myself, I'm a white woman with short hair. I'm in a pink and blue sweater and I'm wearing glasses. I work at Hands in Autism and I am the family and community liaison. So in |

my role I help to facilitate some of these community and state programs. I particularly am involved in the LCC or Local Community Cadres. So Local Community Cadres are the regional networks that kind of feed into the IIACC. So we've had up to eight different regions that are represented in these Local Community Cadres are a combination of stakeholders, medical, educational, family, providers, and most importantly individuals with lived experience. We really are able at the local level, regional level to think about and talk about strengths and areas of need so that we can focus on individualizing services, trainings, and programs that we can provide or help facilitate.

Kind of the foundation of the LCCs, we would call them the four pillars and the pieces that make up the bulk or the most important pieces of our Local Community Cadres are collaboration, training, information, and dissemination. Clearly collaboration means that we do hope that there are stakeholders from all groups involved in our discussion that we use the information that we get from each stakeholder group to promote and facilitate needs in the community. We use, like Dr. Neal said, a variety of informational tools to decide what those are through hearing their voices. Then we are able to share information with the state, with our Hands in Autism team, and with each other to kind of decide on plans and programming that might be beneficial. We have a variety of trainings that we provide or have access to that we can decide or we can decide together in our stakeholder groups, in our Local Community Cadres if they might be needed or could be utilized in each region.

And then dissemination, We have many materials that we can individualize to make them most beneficial and be able to reach all different areas of the state to share the information that we have. But I think that the greatest impact of LCCs is that we are able to meet together, see each other's faces, even if it's virtually, talk about needs and strengths and collaborate together to help meet the needs of all individuals that have developmental disabilities in our state. It's definitely been a great push that we've had this past year and before that, but particularly this past year to try to make sure that individuals with lived experience are involved in this collaborative effort. Next slide

Tiffany Neal: So the real emphasis and what we want to give time to is hearing from our panelists. So Lexi, Amy, and Ryan were able to connect with us in advance and talk through some of the questions that we have posed here, so I'm going to open it up to them to share more about why we engage in these efforts,

Amy Shamanov: Is it time for us to talk?

Tiffany Neal: Yes

Amy Shamanov: Thank you. I guess I'll get started since I'm unmuted. So reintroducing myself, I'm Amy Shamanov, I'm non-binary I use the pronouns they and she interchangeably, and I am a white person with glasses, long dark brown hair, and a pink flannel, and black T-shirt. Our first question is why do you engage in these efforts? Our first bullet point here says we have a vision for a better future for other people with

developmental disabilities like autism, ADHD, and other conditions like this. I only got involved in advocacy in about the last year or so. I wasn't diagnosed with autism or ADHD until I was in my late thirties. I'm now 41, so the advocacy space is very new to me, but what I want to do is share my story so that other people in the future or even people now can connect with me and whether it be a parent wanting to help their child, whether it be somebody in the community who does service work for people with various disabilities, or other self-advocates connecting with each other. I think we all kind of look at we want the future to be less ableist, more accessible, and better access for everybody regardless of support needs.

Ryan Steiner:       I'll go ahead and go next and answer it. I engage in this because I spent most of my life trying to pretend like I wasn't disabled, trying to hide from it. I was diagnosed as a kid and I grew up in an institution and just didn't really like the way that society sees autism, and I wanted to be a part of that change in perspective, especially since my daughter was diagnosed with autism when she was three, and so I can't watch her live the same things that I lived, and so I've become a part of it and it's actually kind of healed my own childhood issues by being a part of the change. So I enjoy being here for that.

Lexi Westerfield:   This is Lexi Westerfield. I'll go next. My idea of why I engage in advocacy efforts is because the intersectionality within disability is so important to me, especially the interconnectedness between with multiple disabilities. I myself am legally blind, autistic, a wheelchair user, as well as have other chronic health conditions. So I think a big challenge for me is autism in the scope of multiple disability. I think it's really important to advocate for autism among multiple disability individual people with multiple disabilities because I wasn't diagnosed with autism until I was in my twenties and I had a developmental disability diagnosis, but I didn't have the autism diagnosis and a lot of that had to do with my neuro and vision conditions that made it hard to diagnose.

Tiffany Neal:       Next slide. Amy, Ryan?

Ryan Steiner:       I can go and I keep forgetting to say, I'm Ryan, I'm a white man in a plaid shirt, glasses, and a hat. Then I said all that and I forgot what the question was. Okay, so I kind of touched on that and my last answer is that by my voice being heard, it's kind of healing a lot of the misunderstandings that I had throughout my life and I feel like I can better explain my experiences because people take the time to listen because there has been such a new emphasis on lived experience and people learn about autism and stuff, so people are more open to hear what happened and I find that very healing.

Amy Shamanov:       Yeah, just kind of springboarding off of what Ryan said, I also have found it very healing to connect with other people, every stakeholder that's involved in this. We have a bullet point here that says it's a very welcoming environment and I would have to agree with that. I always feel free to share no matter what the subject matter of our talk is on a given day, if you have a thought as a person with a disability, if you have a thought that you want to share, it's always respected, it's always heard, and people have always given feedback that it's very helpful for

them to hear it from that perspective because our voices may have given them something that they didn't think of on their own just because they're not experiencing it.

Lexi Westerfield: To piggyback off of that, this is Lexi. I think for me it's really important to have my voice heard because autism is autism spectrum disorder, It's a spectrum, and to get multiple perspectives from multiple people, you get such a wide range of information of lived experience within a spectrum because as people with or without disabilities, we're all unique and everybody has the right to share their story and be heard and we learn from each other, So that's so important.

Tiffany Neal: Next slide. To build off of what Lexi, Amy, and Ryan so eloquently shared in terms of why they engage, we just wanted to provide a couple links so that you're able to attend or engage yourself or if you want to learn more, there are links there. Next slide. So another effort and one that Lexi, Amy, and Ryan have all been involved in has been our HANDS developmental disability and autism ECHO series, and we'll talk more about what that looks like. But at the fore of developing the ECHO and really looking to adopt the Project ECHO model, we wanted to make sure that the topics that were selected, the data that was collected, had a very person-centered community-based design. So we used a couple of internally developed measures as you can see there, interviews with individuals with lived experience as well as working through focus groups, and then now looking at pilot findings in terms of what we saw out of the ECHO and the impacts to really spearhead or continue forward with the ECHO series. Next slide.

Kristan Sievers-Coffer: I'm Kristan. I'm a white woman with the yellow sweater, glasses, and long hair. So Tiffany mentioned the ECHO model, so I wanted to point out on the right side, that's how the ECHO kind of flows. It is a standard procedure within the ECHO webinar that was created out of the University of New Mexico, but we begin with the welcome and some background information and then there's always a presentation by a subject matter expert. So we do many, many surveys to figure out what the topics are that people would like to discuss. And so from those surveys we're able to come to, we have a variety of series which are listed to the left there, healthcare, education, justice and access, behavioral foundations, community provider, and individuals, and caregivers. And so within those series we have, let's say anywhere from six to 10 or so different subtopics that we talk about one of those each week.

And so we have a presentation on one of the subtopics for example, of healthcare. And then after that person does that for 15 to 20 minutes, then we have lots of question and answer about what they presented. After that, then we introduce some panelists who will help weigh in on a case presentation. And again, the case is typically very much related to whatever the topic was that is discussed by the subject matter expert. And this can be any age, so it's not just children, not just adults, but it's all ages. After the case is presented, we have a lot of brainstorming discussions back and forth questions, and talk about what happened in that case, and then we wrap it up and we're done. So it can go anywhere from an hour to 90 minutes. It is the most favorite part of my job. I will have to say that.

| Tiffany Neal: | Next slide. So as we look towards the impact, we want to share some of our data. |
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| Mounika Gottipati: | Hi everyone, I'm Mounika Gottipati, I'm an Asian woman with a yellow top and spectacles and black hair. So as we collect data during our ECHO sessions from all the data we collected, we found to know that majority of the ECHO attendees are individuals and family members, and most of the attendees are female, and around 85.6% is as you can see from the slide here, which clearly indicates that most of the professionals such as consultants, therapist, and counselors which indicate a strong mix of both personal and professional engagement in our ECHO program. Next slide please. Also, among the data we collect, we URP-I is a user rating profile intervention. It's a tool used to assess the perception of the accessibility, feasibility, and effectiveness of the interventions from the ERP scores, which showed a significant increase in participation in the ECHO program with notable improvements in participants knowledge and clarity about implementing the evidence-based strategies, which is a key component of the ECHO program. This suggests that the program effectively enhanced the implementation of participants understanding and confidence in using evidence-based practices in practice. Next slide please. We are almost based in the Indiana state, but also not only in the state of Indiana, the participants was widespread from various different states and also different countries all over the world. Next slide please. This represents overall vision of various participants percentages from various countries. Next slide please. Our panel members will share their voices and their experiences with us. Again, |
| Tiffany Neal: | Lexi, Ryan and Kristan, or sorry, Lexi, Ryan and Amy, would you guys like to discuss the next question, please? |
| Ryan Steiner: | This is Ryan again. I think that one of the things that we talked about before was that a lot of times what I'd like to further enhance it is that when a program gets going and it gets up and moving and people are engaging and then it leaves. And so there's a whole lot of change and I like having that continuity of like continue to talk to the same people and work through the same programs and keep the momentum because we have to start over at the beginning. Every time a program gets cut and we have to start anew. |
| Lexi Westerfield: | Something I think is really important is connecting and networking for people with lived experience. In the context of our day-to-day lives, we might not have very much interaction with other people with lived experience, but when we come together virtually or in person as individuals with autism and related disabilities, it makes us just feel I guess people relate and it just really, it builds us up. |
| Amy Shamanov: | Sorry, I temporarily got booted off. We had a mini power outage here, but I came back just in the time it looks like. So the question is focusing on what would further enhance these experiences? I have to agree with Lexi. I think just the opportunity to connect with each other and not just other people that are working professionally in this space, but with other advocates, it helps you feel less alone because we may or may not have other people with the same disabilities in our social circle. We may not have a very big social circle or any social circle at all. So it gives us a chance to connect with other people and at least at the very, very |

minimum feel not so alone in our experiences. I think it also, it's helped me learn a lot from different perspectives because a lot of autistic people have reported struggle with what's often referred to as cognitive rigidity or black and white thinking. I refer to it as a strong sense of justice, but it can help to hear other perspectives as well. So when I started in the advocacy space, I was coming in real hot with like, no, you can't do this. You can't do a ABA, you can't do these things. Listening to other people who have had different experiences has helped me kind of, okay, really what we need to do is we all need to work together to better all of our lives. And yeah.

Tiffany Neal:          Next slide. Lexi, Amy and Ryan, would you like to talk through this question?

Amy Shamanov:     I wanted to lean on the virtual and in-person options. Definitely I think every panel discussion, every conference, everything ought to include a virtual option where the virtual attendees are included in the discussion because like Lexi mentioned before, a lot of disabled people have multiple health conditions and coming to a crowded event with a lot of people, especially if you're immunocompromised or you have other conditions that make that physically difficult, it can be very isolating for people. So having local events, considerations for different people in the lifespan I see our, we talked about a lot of things are oriented around children. It would be really interesting to see it expand to all stages of life, not just childhood or even early adulthood, which there's a lot of emphasis on, but middle aged aging, aging into autism is something that I'm experiencing now as a middle aged person with a uterus. I'm perimenopause and it's turned my world upside down. So just more services and knowledge around that. I'll let others share their thoughts now.

Ryan Steiner:         I'll go, Ryan, it's funny that you say that about the aging. I know that you've been on here and earlier someone had come on and they were talking about autism speaks and how they're changing how that is, and they're doing research into autism and aging, and that's something that I really appreciate that's newly emerging because I too am an autistic person who is aging, so I'm not only dealing with the aging parts or the autistic parts is that a lot of my fears are now coming true because of a fear of the unknown. But we all get older and that's one of the things that I had talked about when we were talking about this conversation was actually is that I find myself jealous of the friendships that are set up for people with autism and developmental disabilities now. It's like, oh, there's this friend group and let, let's make sure, and I had to seek this out.

I had to seek out friends and I had to be able to connect and I do that through things like HANDS and stuff like that. So I hope that it becomes more natural for neurodivergent people to be able to find each other. And I definitely have to agree with what you said about virtually because if it were not for social media, I would not be sitting here today because I had to develop into the advocate I was and learn my social skills virtually before I could even apply them outside of my home because I was that afraid to leave the house. So I think that there's probably a lot more people out there who could be more involved if there was even virtual options.

Lexi Westerfield:     This is Lexi, I also appreciate how in the era we're in today there is services or groups or whatever, providers or whatever it may be that focus on a disability, a specific disability, and then the ones that focus on a wide range of basically anybody with a disability or anybody with a developmental disability. It gives people a chance to interact on so many different wavelengths and basically platforms, whether it is virtual or in person, but as a platform of this is autism specific, this is cerebral palsy specific, or this is for anybody with a developmental disability, or this is for stakeholders and people with disabilities. There's such a wide range of basically ways to interact virtual or in person and that's really appreciated.

Tiffany Neal:     So sorry, hit the wrong button. Thanks for sharing your experience and providing some recommendations for those that are on the call as well in terms of what has really been supportive and moving ahead. This is just a quick link for those of you that have not had the pleasure of joining an ECHO session. If you'd like to join one of ours or learn more about ECHO, we have the links there to learn more. Next slide. So in closing, next slide. We have a range of opportunities aside from the Autism Engagement Network, but really wanted to highlight this and that we've had a high amount of people engaging individuals such as Lexi and Amy and Ryan that are true champions and have really been able to speak and represent their experiences. So we have information there if you want to get an informational packet about this program or this network as well as other resources or if you'd like to learn more, feel free to reach out. Thank you.