

## 2023 KT Online Conference: Understanding and Respecting the Strengths of Your Target Audience

*Presenter:*

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FELICE TRIROGOFF: Next up, our panel is Understanding and Respecting the Strength of Your Target Audience. And we will begin with Sandra Vanegas. Oh, perfect. You're already on camera. She will be talking about empowering families of children with developmental disabilities in low resource households.

Sandra is currently a research assistant professor and director of research for the Texas Center for Disability Studies at the University of Texas at Austin. Go Horns. Sandra, do you mind self-describing? And I'll hand it over to you.

SANDRA VANEGAS: Sure. So I'm a Latina woman with dark brown hair, brown eyes. I'm wearing a blue top with white polka dots and a black blazer. All right. So I guess we'll get started.

So thanks, everyone, for joining and for listening to my presentation. Hopefully there'll be a lot of great conversation. There we go. So my work is really focused on improving the developmental experiences for children with developmental disabilities and their families, especially for families that are from racial and ethnic minority communities, as well as from low resource communities.

We know, especially for these families, they experience a lot of significant disparities, not only related to the services that they need for their children but also just in general. They may experience challenges in finding providers and therapists who are trained to support their children with developmental differences. They may be covered by Medicaid or may have very limited coverage by their insurance, which may make it really challenging to get therapies and services.

They may reside in environments or neighborhoods where the schools have much fewer financial resources, as well as other types of resources. So this limits the types of support that children might be able to get in the school system. These families can also experience housing and food insecurity, which creates more stressful environments for the families. And when we think about children and all the different aspects of development that we want to support, we can think about, is their neighborhood filled with playgrounds and parks and other types of resources that can provide opportunities for playing with their peers or getting to know and providing different experiences?

For families who are from racial and ethnic minority communities, especially if they're from-- they speak primarily another language besides English. They may experience a lot of discrimination or bias not only

in their access to their communities, but also in receiving services from their therapist, from their medical provider. And then this can also impact how much information they can access related to their child's needs. And then if they're from an immigrant background, there may also be concerns about immigrant status and potential deportation and what that would mean for the family structure.

So these are a lot of stressors that are present in these families' lives. So what are some things that we know can have a positive impact? So we know that when we examine families that feel empowered, we know that they tend to have more understanding about their child's needs.

And then with this knowledge, they're able to navigate these service systems much more effectively. And they have greater confidence, so they know what their rights are. They know how to ask for what their rights are, and are more successful in achieving and obtaining services that they need.

This also translates into fewer concerns related to mental health on behalf of the parents. The child also is reported to have fewer behavioral concerns, and this may be due to some of that knowledge and greater service access that families have. And all of this results in having reduced caregiver stress, which we know can have a positive impact all around-- not just for the child, but also for the family structure.

So what are we doing to address these needs for families in low resource households? I'm the PI for the ASPEN program study. It's an intervention study that is designed to really empower families. And I'll tell you a little bit more about it. So ASPEN stands for the ASD Screening and Parent ENGagement Program.

So a few years back, we realized that there was a significant need to have a program that was culturally adapted for families, and that was really aligned with what the families needed and wanted, especially in early childhood. So we created this program, and it's designed to really empower and train and coach parents with strategies that they can incorporate at home. So it's things that are embedded within the natural environment, and can really be helpful for families to feel empowered and to have a positive change on their child's development.

So this program covers parenting, stress, and social support networks. We realize that families that are too stressed out may not be able to benefit from a program, so we made sure that we started off the program by talking about this-- and developing strategies and identifying support people in a family's lives that could be there to assist. We've also incorporated peer support into this program. So we have parents of usually older children with disabilities who are part of the sessions so that they can share their lived experience with the families.

We provide coaching on naturalistic developmental behavioral intervention strategies. So these are ways that families can directly connect to their child's developmental state or stage, and really help scaffold their development. And we recognize that a lot of these programs are out there, but very few are developed intentionally for racial/ethnic minority and families in low resource households.

So we made sure to include examples that looked like the families that we were serving. And recognize that the types of toys you might have at home may look a little bit different-- or the types of play that you

engage in may be a little bit different. But really connected to what families have available and are able to do within their homes.

So as part of this intervention, we've been focused on families who have a young child-- so between 18 months through six years of age. The child can either have an autism diagnosis or a high likelihood of autism. We know that many families, especially from low resource households and racial/ethnic minority backgrounds tend to not get a diagnosis until much later in the child's life, so we didn't want that to be another barrier for families who participate in this program.

And then we were also focused on families and low resource households. And we define this as, basically, families had to meet one of these three criteria. So they either had to have Medicaid as their insurance provider, the primary caregiver had to have a high school or lower education, or the household income was 200% of the federal poverty level or lower. And to make sure that we were providing resources that were aligned with where the families lived, we also restricted participation to families who resided in Texas.

So next, I'll show you some characteristics of the children. So far, we've had 72 children enroll in the study. This is based on the study entry data that I'm showing you here. Most of the children were male, and most of them are Latino-- what you would expect in Texas.

A lot of the children do actually have a diagnosis, and this may be an artifact of where we're getting our referrals, since many of the local pediatricians and pediatric neurologists are referring their families to us. But then you also see some children who don't have a diagnosis and may have other developmental disabilities, such as speech language impairment or developmental delay. And then for those who do have a diagnosis, it's pretty young-- so almost 2 and 1/2, which is lower than the national average. But our age span is spanning quite a bit, from zero to six years of age.

And then some characteristics for our caregivers-- so all our caregivers are female. We do have quite a range of ages of the mothers or maternal caregivers. We do have some female guardians of some of the children in the study. And most of the caregivers were born outside of the US, so that's something else to think about, in terms of this data. And then most of them have a high school or less education, most of them are not employed. And then the majority of these interviews that we conducted with caregivers were completed in Spanish.

So the data I'm showing you today for family empowerment is based on the Family Outcomes Scale. Yeah. So this is a parent questionnaire that's often used in early intervention evaluations. And it's designed to understand what does the family know and what do they know about how to help support their child's development.

So there are four different areas that it looks at-- so understanding children's strengths and needs, knowing about rights and advocacy, how to help the child develop and learn, having support systems and access to the community. So as you can see, the overall scores-- there are a few areas that are pretty high. So here, the average ratings are from 0 to 5, with 5 being the highest, indicating greater empowerment.

So we do see that there's pretty close to two 4's for helping children develop and learn and access to the community. But then we do see that knowing about rights and advocacy and having support systems is a bit lower in some of the other areas. So we then looked at what are some of the other characteristics of our sample that are related to family empowerment.

So we looked at parent nativity-- so for family caregivers that were born in the United States or outside of the US. And we do see that there are two areas where caregivers who are born outside of the US reported much lower scores than caregivers that were born in the US. Specifically, those two areas where we saw lower scores-- so knowledge about rights and advocacy for children and having support systems. So this suggests that caregivers who were born outside of the US have less knowledge about this, and may have fewer support systems available to support their caring for their child.

So we also looked at a couple of other characteristics. So we saw that caregivers of older children reported lower access to support systems. Older caregivers reported lower access to support systems as well. Parenting stress was related all around, where caregivers who had higher parenting stress also reported lower empowerment. And then family quality of life was also positively associated with greater empowerment, which we can expect. If you really feel empowered and have all this knowledge and support, you may enrich your lives.

So just overall, some of the things that we've been doing for knowledge dissemination related to this study-- we've been doing several parent workshops, specifically to address some of the needs of some of the families. And these are open not just to families who participate in our study, but they're open to families all over. And they're not specific to Texas, either.

We've done a few on the early signs of autism. We've done some on mental health and children with disabilities and families and caregivers. And all of these workshops have been delivered in English and Spanish. And we make these available on our YouTube channel so that families who miss it may be able to go back and watch it. We've also done a lot of engagement with our local providers. So we have partnerships with Early Head Start and Head Start programs, as well as home visiting programs, so that we can connect with the families who may not be connected to other systems of care, such as a local pediatrician or a neurologist.

And then we've also created a social media channel. We've developed a theme for each day where we talk about developmental milestones, disability services. We focus on a specific disability and share some more details about what those disabilities are. We provide some tips of the week, where we share different strategies that families can try at home to support their child's development and also identify local and regional resources that families can access, too, for different types of needs.

Just a final slide on just some recommendations. So in engaging with these communities, especially underserved communities, I think it's really important to identify what they specifically need, and what that community looks like. For example, many of our families, when we first started this project, really reported that they needed more respite services, so we were able to compile information from all the different providers that provided respite so that they could apply or see if it would work for them.

And then evaluating circumstances-- for example, respite, as I mentioned-- it's important to also identify and improve the policies that may limit or create barriers for underserved families. So one of the things we did was to make sure that our enrollment criteria wasn't limiting families' participation who most needed it, for example. In terms of research recommendations, it's really important to identify support that exist in the community.

So one of the things-- because our program is completely virtual, we want to make available tablets and Wi-Fi hotspots to families so that they can access those. We also connect them with other community organizations that can provide other types of support that are not connected to our specific program. We've tailored our approaches to match the needs of the community, so we develop all our materials in English and Spanish We have a community advisory board that helps us shape some of our approaches for engagement.

And we've embedded ways for our research to give back to the community. So we've tried to do a lot of outreach and a lot of community education through workshops and other formats to make sure that families-- the things that we know as researchers is really getting out to the communities and the families that need it the most. So I think that concludes my slide. And here's my contact information, should you have any more questions or wanted to reach out afterwards.

FELICE TRIROGOFF: Great. Thank you so much, Dr. Vanegas. I really appreciate your research recommendations and giving back to the community and making sure what you've learned is being shared back. Thank you. We will now move on to our next panel. If I could ask Regina and AJ and Lane to join me-- great.

Regina Firpo-Triplett runs the Innovative Public Health Small Business dfusion, which creates digital innovations for health. And during their time at dfusion Lane Edwards has worked as a project director on a number of online learning projects, targeting parents discussing sexual health with their children with IDD, young adults on the autism spectrum, working to build relationship and communication skills, and pharmacy staff selling non-prescription syringes to reduce bloodborne disease.

AJ Tanksley served as a scriptwriter for dfusion during the summer of 2023, creating video scripts designed to impart relationship and communication skills to autistic young adults. Regina and Lane and RJ, are you ready? And please don't forget to self-describe. Thanks.

REGINA FIRPO-TRIPLETT: All right. So I'm Regina. I'm happy to kick off this presentation working with autistic young adults to develop effective video-based healthy relationship skills training game show. I am a white woman with dark brown hair with a generous amount of gray. I wore glasses and a green blouse. And I'll have the contestants-- since this is a game show, I'll have them introduce themselves in a minute when we welcome them to the game.

And so this is The A List. We thought we'd do something a little bit different. This is the most popular public health game related to how to fully engage autistic young adults in creating an intervention for autistic young adults. So happy to be here. And I want to invite our contestants, who've never been part of a game show like this to introduce themselves, and thank you for playing.

AJ TANKSLEY: Hi, everyone. I'm AJ-- they/she/he. I am a brunette-haired, femme-presenting person with my hair held back in a bun. I have glasses on, and I'm wearing a dark green turtleneck and a beaded necklace, which you may see me play with once in a while.

LANE EDWARDS: And I'm Lane. My pronouns are she and they. I am a white person with pink, shoulder-length hair, a headset, and a black floral shirt on.

REGINA FIRPO-TRIPLETT: All right. I hope you two are ready to play. But first, I want to say we actually do have objectives for this game show, and it's for y'all to learn how to authentically engage autistic young people if you happen to be creating a skills-based intervention. And how to do that in a way that can engage them also in the creative process-- the scriptwriting, the acting, working on the set. And that you're not only going to learn from our staff and consultants contributing to the project, but also what we've learned from all the amazing young adults who were part of the project.

And so that's all that you'll learn. And I do want to thank our sponsors, most importantly NIDILRR for funding this phase II project that we're developing-- the skill flix for young adults. So very happy to have their support, and you already heard a little bit about dfusion.

So I think we'll just go ahead and talk about how the game show works. Basically, we'll be throwing out questions. The contestants will have to buzz in or raise their hand if they want to go for the first answer. The folks who answer first get 100 points. And then the other contestant can share examples, personal insights, lived experiences related to the work.

The points will be very carefully documented so that we know exactly who wins at the end, because there are some great prizes. So to start us off with an easy question, have you learned a lot about creating educational content with and for autistic young people? AJ.

AJ TANKSLEY: So I definitely have learned quite a bit, in addition to drawing on my own experience as an individual on the autism spectrum. I also had the chance to write for characters who use augmentative and alternative communication devices. And one such character was Noah, and as I was researching Noah and being able to get into his head to write good quality scripts for him, I got the chance to also go down a couple of research rabbit holes concerning AAC communication users. And it was very enjoyable to learn about that as well. There's a lot that I, as a hyper-verbal autistic person, got to learn about individuals who may not necessarily be hyper-verbal or who may need to use AAC devices in order to communicate.

REGINA FIRPO-TRIPLETT: Great. Lane?

LANE EDWARDS: Yeah, I just wanted to take it back to the broader learnings. I'm one of the key project staff, obviously on the autism spectrum. And the thing that I think really struck me throughout all of the work we've done so far is just how much every individual person brings such a different perspective.

And it's something we already knew. You don't want a sick person. You don't want an autistic person, as people say. But just having the opportunity to reach so many different people. We've done focus groups.

We've done our phase I study. We've got an advisory board-- again, we've got scriptwriters. We have actors on the autism spectrum to create the videos.

So we've had so many different perspectives snowballing to create really insightful just experiences and personal touches to each of the characters and their stories that they go through as we develop these different skills for their specific situations. So yeah, I guess we learned a lot about how to reach a lot of different people because different people are able to be reached in different ways, and we learned a lot from reaching out.

REGINA FIRPO-TRIPLETT: All right. Thank you. So this is a chance for the audience to applause. And we have these throughout for questions, but we're saving questions to the end, so thank you. But you are welcome to applaud at any time.

So next question-- what do you think about while navigating a neurotypical world? And how does this inform your work? AJ?

AJ TANKSLEY: So oftentimes, when I think about navigating a neurotypical world, I focus on my lived experience interacting directly with other people and the fact that a lot of neurodivergent people-- not just myself, but also many individuals who may have comorbid conditions with autism as well-- how a lot of times we don't always receive a whole lot of empathy or support from people in our lives, and how we may have to fight a little bit harder to advocate for ourselves, even when we're running on limited battery or resources. So in my scripts, I implemented this by focusing on the concept of neurotypical people meeting neurodivergent people where they are at, and basically focusing on extending this empathy towards autistic people that we need the most going about in our day-to-day lives.

REGINA FIRPO-TRIPLETT: Lane, anything to add?

LANE EDWARDS: Yeah. For me, approaching this work, I think it's something that is communication skills and social skills intervention. The part of my life experience that really stood out to me was that there are a lot of times in an autistic person's life where there's a lot of pressure to conform to typical expectations of communication and behavior and all these other things. And a lot of people have a lot of fatigue with that pressure and being told how to act all the time.

And I found it really important to balance the very real reality of living in a world that is centered on neurotypical communication styles and things like that. And so trying to support people in saying-- not, this is how you should act, but trying to untangle some of the expectations that might not be clear to everyone. And say, here's a couple options for how you might handle the situation. Here's why people maybe are holding this expectation for you, and here's a couple of different ways, depending on your desires, your abilities, what you want from a situation, you can approach it.

So I really wanted to take it beyond helping people mask more, because as a ... not just a person, it's sometimes hard to figure out how to even take off a mask. So we want to explore both how to meet expectations sometimes, and also sometimes how to take off that mask and find and navigate it in your most authentic way to yourself.

REGINA FIRPO-TRIPLETT: All right. Great. Lots of points being interred here. So we've got three categories of questions here-- center and value autistic perspectives, create space for autistic people to give substantial input and feedback, and employ autistic people in a variety of roles. Where would you like to start, contestants?

LANE EDWARDS: I'd like to start with the top two, and maybe we can go in order.

REGINA FIRPO-TRIPLETT: OK. We're going to go with Lane's advice and start with the top one-- center and value autistic perspectives. The first question here is how would you want someone to demonstrate that they center and value autistic perspectives? Lane?

LANE EDWARDS: OK, I'll take that if you can advance. So autistic voices have had a pretty long history of being ignored and raised in interventions that are intended to serve us. So the first thing we knew that we wanted to do with this project was create space for autistic adults to share their perspective and let us know what specific things we could do to just make them feel heard. So in creating this space, we wanted to make sure we were being accessible, that we were creating comfort, and that we were providing as many options for different types of communication as we could.

I know I tend to get some phone anxiety, email anxiety, Zoom anxiety. There's a lot of stuff-- just having a camera on and being able to see your facial expression all the time and getting caught up, monitoring-- anyway, there's a lot of loaded stuff with these communication things. So we did a couple of things to make it more accessible-- a lot of the things being done here. We, of course, use auto-transcription and virtual meetings so people with auditory processing challenges-- we provided the option to have a camera on or off. Can you hear? Have the camera on or off without pressure.

And we also have the opportunity to engage verbally or in the chat for non-speaking advisors. We also created space to contribute without attending any group meetings via email or one-on-one meetings. And a lot more-- pretty much any time we contacted our advisors or our focus groups or anyone being involved with the work, we tried to provide a whole host of options to address different accessibility needs and levels. Yeah. So going from there, we found it important to understand how language and symbols were able to demonstrate our relationship with the community. And I think AJ has possibly some insight to share.

AJ TANKSLEY: Yeah. So the biggest thing is that-- granted, the neurodivergent and especially the autistic community is not a monolith, so it's hard to represent one symbol to represent every single autistic person who ever lived. But one thing that we want to make sure of is that the symbols that we use don't necessarily reflect stereotypes and assumptions that neurotypicals may have about autistic people, and that they reflect more of our experience as a spectrum. And Lane had a really wonderful example from when they were working on the filming process of how this was implemented.

LANE EDWARDS: Yeah. So we've always made the choice-- we tend to use the infinity symbol, the neurodiversity infinity symbol instead of a puzzle piece because we had it shared with us. Some people feel like the puzzle piece can represent autistic people being a puzzle or having a missing puzzle piece or even finding it infantilizing. So we tend to use a neurodivergent symbol to represent acceptance and



celebrate the diversity of autistic experiences. But at the same time, we like to recognize how diverse the autistic community is.

One of our actors, who is on the spectrum himself, he proudly has a puzzle piece tattoo with a ribbon and puzzle pieces in it because he said he's always felt life is a bit of a puzzle for him. So it's good to not be absolutist, but also to be aware of what implications we have with the different things we choose. Things like language as well-- we choose to use identity-first language instead of person-first language. Because it's the broad preference of most of the autistic community, but that is always going to be different for different people.

And it's always important to see how people self-identify and to refer to them in whatever way they end up referring to themselves. So basically, we just wanted to make sure that we were always showing walking the walk and talking the talk, that we are empowering self-expression using the strength-based approach rather than masking or pressuring adults to behave neurotypically.

REGINA FIRPO-TRIPLETT: So let's move on to the next category. Thank you for the applause. That was for Lane and AJ. Create space for autistic people to give substantial input and feedback. So the question here is, how do you create opportunities for input and feedback from autistic young adults?

LANE EDWARDS: I can take this one also. This is going to be the most familiar looking part. This is something that a lot of us do in advisory groups and focus groups, as well as participants in our studies and by usability testers. With our focus groups, we were able to get input from the beginning. We returned in a very iterative process for every milestone.

We used this to get a lot of topics we were addressing, the skills people wanted to look at, the relationships that were most important to them and the different ways of that. We could use language to be more accessible and more resonant with the people that we were working with. We had observational data.

We also did our phase I study, where we did a short pilot of a smaller number of videos with about 20 young adults on the autism spectrum. And for that, we got a lot of interesting observational data from these roleplay sessions we did. We had online surveys with a lot of opportunity for feedback on the resource. And we did remote interviews with all of the participants, really focused on learning what worked for them, what didn't work for them, and what they would want to see. We made 150 videos for our phase II.

So what we could do to really cover as many of the different situations that were a struggle for people as possible. And so this is the traditional part, but we also were able to do a lot of really interesting other things to involve young adults on the autism spectrum, which I think have really given us just an authenticity and a closeness to the experience that people are having to make it a really cool resource.

REGINA FIRPO-TRIPLETT: Thank you, Lane. All right. So we're down to our last category-- employ autistic young people in a variety of roles. And the question is, can you share a little bit about the perspectives that you brought to the project? Whoops. Did I do that wrong?

LANE EDWARDS: AJ?

REGINA FIRPO-TRIPLETT: I think we're back-- yes.

LANE EDWARDS: One more screen.

REGINA FIRPO-TRIPLETT: Yeah.

LANE EDWARDS: Yeah.

REGINA FIRPO-TRIPLETT: OK. I think that-- AJ, go for it.

AJ TANKSLEY: So my big perspective that I brought to this particular project is a focus on assertiveness in communicating within relationships. In my own life, I've had to basically learn how to be assertive with different amounts of bumps in the road, so to speak. And so I use that experience with having to use assertiveness in my own relationships with the characters of Hector in the scripts.

A lot of times, when they communicate with each other, they have to balance being assertive with being willing to compromise with each other. And so a lot of those scripts revolve around that interplay of being assertive versus being compromising. And it's, in a way, a very universal experience in many relationships. And those scripts in particular were a joy to write because I was able to explore that interplay so much.

REGINA FIRPO-TRIPLETT: And Lane.

LANE EDWARDS: So hopefully, everyone will be able to hear me for this one. But part of what AJ is getting to is that we were able to employ a lot of autistic people in a lot of different roles. Project staff, like myself, are the center and building blocks of the project-- an opportunity to really frame how we approach building communication and relationship skills, to build trust and connection with other autistic people contributing to the project, able to center autistic perspectives and provide insider knowledge on these kinds of things, which then led to this great opportunity to work with a lot of-- we had five script writers, all on the autism spectrum, all young adults who were able to share their authentic voices and personal experiences to represent things very true to themselves. These people all had very different experiences, different skills, and different challenges that they were navigating in their lives.

We were able to recruit all those script writers based on connections and relationships we made in phase I, as well as personal connections that we have. And something cool that just really resonated was we also ended up casting majority autistic actors. So 60% of our actors or characters on the autism spectrum were played by autistic actors, which I think allowed the characters to feel very believable and authentic.

They had very natural-- we would just be able to say, oh, for this theme, like let's have this character stimming. And that person was able to be like, well, what would I really do in this? What would my stim be in this situation? Which I think really let it feel organic.

And a cool comment that I got from several of the actors when they were looking at their characters was saying, whoa, this character is me. I feel like this is just a story about my life, which was what a great opportunity we had to build between having these fabulous scriptwriters with all these awesome different experiences, and then able to take the time to really find people who resonated with those roles.

We had one guy who he really struggled. He lived at home. He struggled with his communication for a long time before beginning to realize that he was experiencing speech loss, and that he wanted to use AAC stuff. And that he was very early on in his journey with exploring AAC, and then he was representing a character who also used AAC, and it was really cool to see how comfortable using the device that we were able to provide in the scenes was.

We had another character talking about how she was navigating sex and relationships and intimacy, especially as an autistic trans woman. And that a lot of the things that we had about sensory issues and noticing intimacy cues really resonated with her own experience. So it was just awesome to have it just feel true to life, and it was touching on the things that were an important priority to our population.

REGINA FIRPO-TRIPLETT: Thank you. What about strategies to engage young autistic people in the creative process? And I know we may be running out of time, but I trust we'll get a five minute warning if we have five minutes left.

LANE EDWARDS: We're close.

AJ TANKSLEY: So one big thing for me was being able to set my own hours because I have a sleep disorder that can make it difficult for me to work a typical 9:00 to 5:00 schedule.

LANE EDWARDS: And so AJ was one of our script writers. And for AJ, we definitely found that setting independent hours and working really independently played to a lot of his strengths. However, we had a lot of different people with a lot of different strengths and support needs, and we took a really long time for the scriptwriting process. And so we were able to really sit with all of those needs and work on meeting them however we could.

We had some people who wanted flexible hours. We had some people who wanted a lot of one-on-one meetings to collaboratively work together. We even had people who said, I'm just having executive functioning challenges. I don't need you to help me, but can we just sit on a meeting and work together and have this body doubling productive space? And so we just were able to take our time to support and creating structure when necessary to provide clear written directions and feedback opportunities for accessible meetings, and just showing that we were really willing to meet specific needs however we could, no matter how much time it took.

And I think we've got this next slide that just touches on the things that I just mentioned-- check-ins and collaborative writing and taking iterative steps to give feedback. Someone might just leave a question mark, and say, I don't really know about-- maybe I struggle with assertiveness. Can we talk about assertiveness together? So we could figure that out.

And since we're running out of time, I'll move on to what we were also able to do on our video sets. Because working with autistic actors is such a pleasure, and it also has its own challenges because a set can be a really overstimulating and stressful place to be.

There's a lot of pressure. There's a lot of bright lights. There's a lot of strong smells and sounds and all of this stuff going on. And often, the days are pretty fast. So we were able to do some things to work with our autistic talent to make sure that we were trying to take everything we could into consideration.

We worked to always let people know what to expect ahead of time, since change or unexpected things like that can be very challenging for people on the autism spectrum. Every evening, we were able to send out stuff like our shooting order and our lunchtime and our plans for how the day was going to go. We also started the start of the day with a little discussion about that.

We definitely checked in with everyone about any sensory sensitivities they've made. We thought about it with our prop clothing and their food restrictions and smells and things like that. We also made sure to provide a quiet sensory room for a break. Another guy, he was most comfortable taking a walk outside if he needed to de-stress. So we were able to take a walk around the block between scenes.

So really, just making sure we could figure out what people needed-- make a space where they could voice what they needed. Thinking about even giving acting feedback for people who maybe don't understand as much metaphorical language. A lot of the time, there's a lot of metaphorical stuff, where someone will say something like, oh, let's try it again, but with more oomph or something. And someone's saying, I don't know what oomph is.

So we tried to be also really specific when we were giving that kind of feedback, which not only is beneficial to our autistic actors, but I think is beneficial to everyone. Really, all the things that are accessible, of course, to autistic people, I think, just make life more accessible for everyone.

REGINA FIRPO-TRIPLETT: All right. Thank you, Lane. Uh-oh. OK. So I know, AJ, you mentioned-- in talking about your experience writing scripts, you made reference to the meat in the middle scripts. So I want to know what knowledge and communication skills can neurotypical people build to meet in the middle?

AJ TANKSLEY: So when I, in particular, was working on my scripts, I came across a concept called the double empathy problem. And the double empathy problem is research that was uncovered, basically revealing something I've had a gut instinct about for a while, which is that oftentimes neurotypical people-- that is, people without autism-- are not willing to always meet autistic people on their level and give them empathy, whereas autistic people are often expected to give empathy to people who are not on the spectrum. So navigating that was something important that I learned when writing these meet in the middle video scripts, and it was a very fascinating process learning through research something that I've had a gut instinct about most of my life. Lane.

LANE EDWARDS: Yeah. So jumping off of this double empathy theory-- we're wrapping up right now. This is, I think, our last slide that we need to cover, Regina.

REGINA FIRPO-TRIPLETT: One more. We have to give the prizes, so after this.

LANE EDWARDS: OK. And the prizes. So yeah, we were basically-- in all our discussions we had with everyone on the advisory board, we were finding that there is this desire to, of course, communicate better with the people in your lives to build these relationships, but also recognizing that sometimes they need the people in their lives to communicate better with them.

So this idea of bridging the gap and meeting in the middle and saying, I'm watching all of these videos and learning all these things. Maybe you can also learn some things and we can bridge that double empathy gap that is sometimes happening between autistic people and neurotypical people. So we also have a series of videos in the curriculum that we're calling Meet in the Middle videos, which are for people to share with neurotypical people in their lives to help them better understand and better communicate with autistic people-- things like stating your feelings clearly, supporting someone in unmasking, navigating tone differences, and several about relationships and intimacy and not have the sole burden on autistic people to bridge this gap.

REGINA FIRPO-TRIPLETT: And thank you for letting us squeeze that in, because it's a really important part of the program that a lot of folks are resonating with. So we do have some prizes for our contestants. You get to choose between a puppy of your choice, a cash prize of half a million dollars, some Guinea pigs, or this sensory sling. What would you like to pick, Lane and AJ.

LANE EDWARDS: I think I've found that half a million dollars can buy many sensory swings and puppies, so I'm going to go with that one.

REGINA FIRPO-TRIPLETT: OK.

AJ TANKSLEY: I will take the puppy.

REGINA FIRPO-TRIPLETT: All right, Thank you. And thanks for letting us go a little bit over.

FELICE TRIROGOFF: Thank you, Regina, Lane, and AJ. And I believe that there is a video. So I think we can go ahead and play that.

LANE EDWARDS: OK. This is a fun one. It's from our phase I, which we did during COVID. So we actually ended up having to shoot remotely via Zoom, which was an interesting experience. We don't usually shoot remotely, but we learned how to do it during COVID. This one was built off this idea that we were doing some stuff exploring apologies.

And we found several of our advisory board people said, apologies are hard, but I also find myself over-apologizing a lot. I'm a person who's been criticized very heavily for a lot of things in their life. And so they felt like they said sorry too much. So in addition to some skills around navigating their own apologies and receiving apologies from other people, we added a video on working on this instinct to over-apologize with people in their lives.

VIDEO SPEAKER 1: Sorry I missed your call. My phone was on silent.

VIDEO SPEAKER 2: You're always going ghost.

VIDEO SPEAKER 1: I'm so sorry. I keep forgetting to turn the ringer back on after class.

VIDEO SPEAKER 2: Well, I know who not to call an emergency. Don't worry about it.

VIDEO SPEAKER 1: I'm so, so sorry, man. I promise it was a mistake, and it won't happen again. I keep forgetting, and I feel really bad.

VIDEO SPEAKER 2: Sky, when you apologize this much, it makes me feel uncomfortable. It's like you're not apologizing to me, but just in general to make yourself feel better.

VIDEO SPEAKER 1: Oh, wow. I hadn't thought about that. Thanks for pointing that out, Nelson. It definitely wasn't my intention to undermine how you're feeling. I'll make sure to work on that in the future.

VIDEO SPEAKER 2: Thanks, Sky. Miss my call again? What if I was trapped in a burning building and needed your help?

VIDEO SPEAKER 1: I really want to apologize right now because I feel embarrassed that I missed Nelson's call again, but he said that makes him feel uncomfortable. I should use different skills. Well, if that's the case, your first mistake was calling me. I really appreciate your patience with me.

VIDEO SPEAKER 2: Not a problem, not a problem. Hey, I was just calling to tell you about this new show I started watching. Oh, but if I ever am trapped in a burning building, that's on you.

FELICE TRIROGOFF: Thanks, to Fusion for that video-- and Elizabeth for sharing it. I'd like to now invite Sandra and Kathleen back online-- or back on camera, rather-- to facilitate this panel's Q&A. And Regina and RJ and Lane.

KATHLEEN MURPHY: Great. Perfect. Thank you, Felice. Well, this was a really interesting panel. I love that there's such cross-cutting themes for the panel. So I do want to-- I'm curious, Dr. Vanegas. Do you find in your work that over-apologizing is an issue? Or do you see that some of the expression of people on the spectrum varies culturally?

SANDRA VANEGAS: It's an interesting question. Most of my work is with little ones.

KATHLEEN MURPHY: And they're not apologizing, right?

SANDRA VANEGAS: So they have limited language skills. I don't have that much experience with older kids or adults. But I can definitely see the behavior.

KATHLEEN MURPHY: I thought maybe because of your work you would have a broader sense. Sometimes people who get involved in particular issues have someone in their family who has that.

SANDRA VANEGAS: Yeah. I've noticed it in some of our advisory board and maybe colleagues that I work with that are on the spectrum. I think it definitely comes up. So I'm always trying to figure out how do I support them so that they know that they don't have to over-apologize. It's recognizing that everybody-- things happen to everybody. And how do we move forward from there?

KATHLEEN MURPHY: Sure. It's just interesting because we're talking about something-- I wouldn't say it's at the heart of it. But an important aspect is communication, and that's clearly so culturally embedded, so your work is so interesting. And we do have a question from Emma Barrett for you.

She said, hello Ms. Vanegas. My name is Emma Barrett. I'm a student going into disability and critical autism studies-- so perfect panel for Emma. Since so much of your work involves autism research, especially in lower income communities, how can I be better at including often marginalized voices in my advocacy and research?

SANDRA VANEGAS: Yeah. One of the main things that I think really helped to know what to do right and how to engage was to really just get out in the community-- so connecting with community organizations, volunteering for those organizations, participating in their events. And then by way of that, you start learning more about the communities that you're in and working and understand what their needs are.

And I think having those relationships is helpful for when you are developing research projects. You have a community to turn to for support or for advice on how to navigate certain research questions. There might be things that are interesting, research-wise, but they're not meaningful to the community. So I think they can really help center the work and make sure that their voices are coming through in the work that you're doing.

KATHLEEN MURPHY: And you did talk about, because Roberto Sandoval is wondering, Dr. Vanegas-- what medium did you use to disseminate your research findings to the community? And did you use any follow-up means to validate comprehension of information shared? So we know, from what you just said, that you have gone out and met with groups of people, and you also have your YouTube channel, as well as the immediate people who are enrolled in your studies. So I don't know if you have anything more to add to that.

SANDRA VANEGAS: I think that's the main ways that we try to-- that's one of the things we're trying to learn more about. What's the medium that's going to be most effective? We know that, at least with the families that I'm mostly working with, email is not the way to go. It's really about texting, social media, sharing on Facebook support groups, and disseminating through those platforms.

We haven't looked at some of that data to see what are the best ways to engage them yet. I think we've just been trying a little bit of everything, and seeing what sticks. But it's definitely something I think as we move forward, we might need to be more intentional about our approaches so that we can assign effort in the areas that are going to be most effective.

KATHLEEN MURPHY: And one of our attendees is noting possibly a technique to demonstrate impact as storytelling. So turning to our game show. Staying on this same theme of communication and language

and lexicon-- that is not only a Spanish-English difference, but it can be terms that are used within the disability community or certain subsets of that. And personally, I am not familiar, so I'm assuming some other people online may share that unfamiliarity. Could you explain what body doubling productive space is?

LANE EDWARDS: Sure. That is just something-- I think it's come out of a couple different neurodivergent communities, like the ADHD community and the autism community, where just anyone who struggles with executive functioning, where it can be really hard just to even start a task, where putting together the steps, maybe, of just like, OK. I'm going to sit at my computer, and I'm going to turn it on. And I'm going to open up Word, and I'm going to do this work.

It just starts to just-- oh, where do I even start? The steps are hard to approach when you have that executive functioning challenge. And sometimes just having another person there or having someone kick it off and say, OK, let's open up Word is enough to get past some of those challenges.

I know a lot of people do this where it's like, oh, I have a lot of chores to do. I'll have a friend come over, and we'll chat while I clean the kitchen or something. Even if they're not doing anything, it somehow makes it easier. And especially if someone else is doing it, and you're able to pick up on the vibes of what they're doing.

It's just one technique-- I think we had two scriptwriters who we just turned on our Zoom call. I did my specific project work, and they wrote their scripts, and we often didn't talk. Sometimes, we didn't even have video on or talk at all for several hours. But just being in a space together helps. Yeah, definitely like coagulation activity.

KATHLEEN MURPHY: And parallel play. It has also interesting analogies, because you talked about employing people with autism to job supports. Supported employment, and having someone there, which is, of course, used for a variety of disabilities.

Throughout this conference, we've been trying to consistently raise intersectionality as a theme. And given that we had one panel talking about Spanish-speaking communities, are there any ways that you plan to or that you have been engaging people from different backgrounds in the work that you're doing and the outreach of it? I don't know if this is a question for Regina or Lane or AJ.

REGINA FIRPO-TRIPLETT: Lane, it's making me think of the trans-autism intersectionality that I know you put a lot of work into engaging actors with those experiences.

LANE EDWARDS: Yeah. I think a couple things that we've been thinking about is obviously when you're talking about communication and relationship skills, these are super based in cultural norms. So you can't necessarily say this is the way that people expect you to act because it's different between men and women. It's different between different communities, different races, different ethnicities, different genders-- all of that stuff might communicate these things differently.



And that's where we try to not so much say, here's an exact script you can follow. But we focus on skills that hopefully people-- we can explain how those skills might work, and then people can try to apply those skills to their own contexts. So maybe the way that you ask someone how they're feeling-- as a person who is feminine-presenting, often my inclination is a very nurturing how are you feeling.

But we had some guys talking about when I'm checking in on my bros, I'm going to be doing something really different. And I don't want to make them feel infantilized or something by being too tender. That's your guys' business. Maybe some more tenderness is good.

But also we have tried to represent that you can approach these things differently, in different ways. And I know we have had a fair amount. We worked with a couple different people with different sexualities and genders and races on all of our different groups of folks that we worked with. And we tried to represent a couple of those in our videos as well. But yeah, it's definitely something that was very on front of mind when talking about communication that is so culturally bound.

KATHLEEN MURPHY: Yeah, great. Thanks so much for that.