[00:00:00] *(singing) It’s time for meaningful insights, every researcher’s delight! It’s Data Night (end singing)*

Kasha Ely: Hi, Orla.

Orla Putnam: Hi, how's it going?

Kasha Ely: Good, how are you?

Orla Putnam: Pretty good.

Kasha Ely: Great.

Orla Putnam: Cool.

Kasha Ely: Well, we got a lot of great questions from our judges about your project so we're just gonna dive straight into them.

Orla Putnam: Sounds good.

Kasha Ely: Great. The first one is, could you please explain your methodology for the content analysis?

Orla Putnam: Yeah. So for the content analysis, I had all of everyone's answers in a spreadsheet and I printed them out. And we did it very old fashioned, where we printed them out and myself and one of our research assistants in the lab separately coded them into themes. We didn't have a preset codebook, we kinda just went along, we created themes as we went. We ended up having pretty similar themes. Some of the codes were slightly different. Like, for example, I would say, "Healthcare training," and she would say, "Training for doctors." And so I just made both of those, "Healthcare training." So I consolidated our code sheets based on our agreed codes, and then I logged every single one of our codes into an Excel sheet. I made sure to note the frequency of each code because I wanted to tell - I didn't wanna treat each theme the same. I really wanted to make sure that the most popular ones were the ones that stood out. So I grouped all of our codes into subthemes and then into themes, and those were the themes that we ended up going with in the end. So yeah, that's how I did that.

Kasha Ely: Great, thank you. Great explanation. Can you talk about how the ideas that emerged from the content analysis differ from the seven main research areas for autism?

Orla Putnam: Yeah. So I thought it was really interesting that the themes that I found from the free responses overlapped with the questions that ranked the highest of the ones that did. For example, "services and supports" is a question that is in the seven but it's also one of the most popular themes. So I thought that that was really interesting. As we get lower down that list, we see questions that either weren't on the free response thing so they were just completely missing, or it was a few - like it may be a subtheme. Something like the autistic phenotype or genetic connections was a subtheme. And it is not only one of the main research questions, but it is also the highest-funded research question. So I thought that was interesting that that was not a very significant theme from something that came up, but it is one of the most heavily funded research questions. I did think it was super interesting that, because I did weight all of the questions, I could see which ones were most popular - or I could see which ones of the themes were most popular. But since the IACC, the Interagency Autism Coordinating Committee, doesn't do that, they just have all seven questions weighted equally, they do treat them all the same. And I thought that was really interesting, that even though they're all treated the same, they don't receive the same funding and they have kind of inverse importance with the community. So that was super cool to me.

Kasha Ely: Definitely. That's super interesting. You mentioned that the research priorities that emerged from the content analysis of the survey results were similar to the types of research priorities being advocated for by the autism community for years. Did you find any differences in the research priorities advocated for by female or nonbinary respondents, as compared to those advocated by the autism community overall?

Orla Putnam: So there was almost, I'd say like a 90% overlap between the things that I've seen by autistic scholars and advocates, and the things that we saw in this oversampled group of autistic adults from female and nonbinary people. But the biggest thing that came up as a theme, that hasn't come up in previous papers that I've read, is the emphasis on knowing what autism looks like in female and nonbinary people. I should add that after - this data that I'm presenting on is the first step in my project. I also interviewed a group of female and nonbinary people and that was a really big emphasis for them, was really understanding what autism looks in these nonmale people. And that hasn't really come up before.

Kasha Ely: Can you talk a little bit about what those differences might be based on your conversations or your prior knowledge?

Orla Putnam: Yeah. A lot of them really emphasized the fact that they were socialized differently than people who were assigned male at birth. So [00:05:00] like in childhood, they might have felt like they were different but they were never really flagged for autism, because of - I mean, a lot of these people are in their 20s to 40s and so, growing up in the '90s and 2000s, a lot of people just thought that autism was little boys. So these girls and these nonbinary kids grew up just thinking that they were different but they didn't know why. So, yeah.

Kasha Ely: Correct me if I'm wrong, that seems to be a pretty common trend in neurodivergent populations?

Orla Putnam: Yeah. It is a lot of, I think, heavily male stereotypes. We see that as well in ADHD, where people think of ADHD and they think of a kid who's jumping around all over the class. And they don't think of the kid who can't just quite concentrate on their homework but may be quieter.

Kasha Ely: Interesting. Thank you.

Orla Putnam: Mm-hmm.

Kasha Ely: Before we jump into the rest of the questions, can you quickly just tell us how you define nonbinary?

Orla Putnam: Yeah. I define nonbinary as, for the purpose of this study, anyone who doesn't identify themselves as male or female. For the survey, we had "male", "female" or "nonbinary" as an option to select but then they could also fill in "other" with their specific gender identity. And just for number purposes, I linked in the numbers with nonbinary people. For example, we had some people who didn't say "nonbinary", they said "gender fluid" but just to put them into a group, I did "nonbinary", but I do believe that gender is a social construct and a spectrum. And I think that those other gender identities are very valid. And yeah, hopefully we can - I think increasingly, people are making more categories for gender when they are looking at gender-based research. So, yeah.

Kasha Ely: Great, thank you for clarifying. Research and researchers are pretty broad categories. Were the respondents aware of what kinds of research and who the researchers were in framing the survey?

Orla Putnam: No. That was kept intentionally vague. Because autism research covers so much, that as a quote is - it could be anywhere from looking at research in schools to looking at just genetics or some - a lot of people do autism research and it's really - I put that in quotes for the podcast, "autism research". And it's very cell-based but they're looking at implications for autism. So it's a very broad spectrum and I thought it was important to keep it vague because we wanted honest feedback on how they view autism research. It was really like, "What do you think autism research is, and how do you think it should be done?" Granted, we did give them those seven research questions to rank so they could kinda get an idea from the themes that came up in the research questions. Like, biology, infrastructure, support, signs of autism, things like that. So I think those seven questions kind of cover what we consider to be research. But yeah, it was kind of up to them.

Kasha Ely: Great, thank you. To what degree would you say that the autism community is represented among program officers and leaders and federal funding agencies? Would you say that diversification of the workforce at federal agencies is another aspect of this?

Orla Putnam: Absolutely, yeah. Because, I don't think autistic people themselves are adequately represented. If they are represented in those program positions, in a lot of - for example, a lot of charities do things like advisory boards, they still aren't the people in power. They are being consulted but they're not always listened to. And that's kind of in - in participatory research, you kind of think of it as like a ladder of participation. You're either having your research done on and then one rung up is you get to get feedback on that research. Or another rung up is you get to give feedback and they listen to you. And then at the very top is you get to be the one constructing that research and actually listened to and you get to be a valid part of that research. And autism research just isn't there yet. There definitely are groups where there are - where autistic people are the ones making the decisions but, for the most part, I think - I don't even think there are advisory boards at the federal level, I can't speak with authority on that. But I know, specifically with some charities and organizations, it's very much like they're working on it but they're not quite there yet.

Kasha Ely: Mm-hmm. Is this something that came up at all in your conversations with your participants?

Orla Putnam: Yeah. I think there's definitely a sense of discomfort and mistrust with that, because there is a lot of tension between autism researchers and the community and the fact that they don't feel that they are represented. They think that people aren't coming to them [00:10:00] with these questions. They're instead coming to their parents or they're coming to professionals who have been in the field for years but who don't know what it's like to live as an autistic person. So they definitely do, were expressing that frustration of not having their voices heard. And I mean a good example, just to go off on a tangent if I have time is like -

Kasha Ely: Please do.

Orla Putnam: Yeah, cool. A recent study where this was an issue is called the Spectrum 10K Study and it was in the UK. And their goal was to look at the genetic profile and other characteristics of autistic people. And the autistic community was very rightfully cautious of this because it did - it had very much implications of eugenics. They were very iffy on what they were gonna do with the data, they weren't being very clear about where that genetic data was going. And they had an advisory board but it was a mix of parents and adults, and they were very unclear about what that makeup was. There was just a lot of tension, there was a lot of feedback, and they actually ended up putting the study on hold until they got a better idea of, working with the community, where that study should go. So there's definitely some pushback from the community that's very warranted.

Kasha Ely: To go off on a tangent a little bit myself, were there any other strategies that people mentioned that could help build the trust between the community and researchers beyond representation?

Orla Putnam: I think transparency has been the biggest thing. For context, I'm a second year PhD student. I've been really trying to learn about these strategies myself in order to, as my own studies get started up, like, "How can I be good about making sure that my research is something that people wanna do?" So I'm a very early learner in this and some things that I've picked up over the past two years have been definitely just being honest with your participants about where things are going. Something that's really neat that I wannato do in my future studies is requesting feedback on data interpretation. Like if your research question wasn't from the community, at least going back to them and being like, "Hey, I have this brain data," or, "this eye-tracking data. How would you interpret that? What do you think about this?" So kind of just involving them in a way that - where they actually have meaningful feedback. Like if they have suggestions on things to change, actually changing it or giving them a reason why you can't change it. So kind of avoiding tokenism at all costs.

Kasha Ely: Sure, interesting. Have you had a chance to implement that in any of your studies so far?

Orla Putnam: I'm trying to do it with this study. I have all these interview transcripts. And I'm trying to figure out a way to actually do that, where if I don't bring it back to the participants themselves, for data security reasons, I do wannato bring in community members to help me sort through this data and say like, "What do you make of all of this?" So fingers crossed. Yeah, kind of a matter of getting funding towards that and stuff like that.

Kasha Ely: For sure. To what degree, if at all, did you take into account individuals with different identities? For example, did responses differ depending on the gender, age, race of the participants?

Orla Putnam: So I actually did not separate them out by gender, race and age. So far, I've been most interested in looking at the total makeup of those but I haven't really compared the participants. I think later on, if we do a more thorough analysis of the makeup, I think that'll definitely be interesting. But the biggest reason that I didn't do it for this preliminary data is because we didn't have enough males to make that, a fair comparison. Just, yeah. I don't think I had the statistical power to do that. So I didn't do it for this analysis but I think in the future, we are recruiting more males for the survey so we should be more evenly matched up pretty soon. I will say that a problem with our dataset and with a lot of autism research is that it is overwhelmingly white. I think I looked this morning and it - I wanna say it was like, of the data that's coming in, I think 50 people are white and 10 people are not white. It's all over the place in autism research specifically. But yeah, that's an uncomfy thing that we're trying to get better at. But, yeah.

Kasha Ely: For sure. You said that you were planning to continue on with the research, do you have any plans for addressing that in future iterations?

Orla Putnam: Sort of? I really tried to recruit more nonwhite people this [00:15:00] time, I think, just with our survey respondents and online and just trying to get anyone that was difficult because we weren't being very picky. But when I was recruiting specifically women and nonbinary people for the interview, I put like, "We want people of color, we want transwomen, we want people who don't speak," because we did give them an option to do an email interview and things like that. So we tried but it was tricky when it was at the end, kinda just came to first come, first serve, we'll take any data we can get. So, yeah.

Kasha Ely: Let's see. I think we have just one question left. And that is, how can your results inform autism community services?

Orla Putnam: Yeah. So I think the biggest takeaway from both the survey and the interviews was that we need more funding and work towards community services. The biggest thing that came out of my interviews, which I haven't coded yet but just having done all of them, was really just that there needs to be more structural support on a community-wide level to just increase accessibility everywhere. And I don't know what to make from that on a research standpoint, I would really love to learn more about policy around accessibility. But I think, overall, there's just such a big push for there needs to be more funding and more avenues for people to get accessibility, just to go about their life as an autistic person and to not run into barrier after barrier. And with informing the existing community services, I would really like for the existing services to just embrace neurodiversity more than they have. And to really, I don't know, let them be informed by autistic people and not try to train autistic people to be something that they're not. I think the biggest thing, the biggest takeaway that I got from the participants was, they really just wannato be able to live as themselves in a world that isn't really built for them. So kind of being more accepting of that.

Kasha Ely: Absolutely. We have come to the end of all of our judges' questions, but I wanna give you a chance to tell us anything else that you want our listeners to know about your project that we haven't talked about yet.

Orla Putnam: Hmm. I think I'd probably just wanna take this time to promote things that my participants have said, which is really just learning - I think it's important to learn more about autism from the source, from autistic people. There are so many books and podcasts and just creative people out there who, of course I can't think of any off the top of my head 'cause I'm nervous, but there are so many people out there who are just so willing to share about their experiences and teach others. And, yeah, I think really just taking the time to unlearn a lot of the stereotypes that we have towards autism and that people think about autism. There's a lot of emerging research on training neurotypical people to be less ablest towards autistic people, instead of training autistic people to be conforming to neurotypical society. There's a lot out there for nonautistic people to do and I think that is just my biggest takeaway, is just trying to relieve some of the stigma towards autism that exists.

Kasha Ely: That's great. And it's okay that you can't think of anything off the top of your head because we will include any links that you'd like to share in the episode description to any of those resources that you think people should take a look at. So, we'll get together, we'll share those with listeners.

Orla Putnam: Perfect.

Kasha Ely: Very cool.

Orla Putnam: Great.

Kasha Ely: Well, thank you so much for joining. What am I doing? Okay, thank you so much for joining us this afternoon. I've really enjoyed talking to you and good luck in the symposium.

Orla Putnam: Yeah, thank you so much. Thanks for having me here today.