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A PARTICIPATE Research Cluster podcast series for the  
Leeds School of Arts hosted by Dr Joanna Leah

## **Transcript** - Thinking is Material Podcast Episode 2: Priscila Beni on Self-Knowledge of Autistic Traits

<https://participate-research.org/news-events/thinking-is-material-podcast-episode-2-priscila-beni-on-self-knowledge-of-autistic-traits/>

Joanna

Welcome to the Thinking is Material podcast, where we delve into the dynamic intersections of art, design and research. I'm your host, Dr. Joanna Lee, an academic and artist researcher at Leeds Beckett University in the North of England. This podcast explores how thinking itself manifests as a material process in approaches to research, emphasising the creative acumen and adaptability that define the methods of today's creative practitioners. As a mover and drawer, I have always explored how thinking is materialized through research methods. It is inspired by Tim Ingold's thinking and acquiring knowledge on the move, where thought is woven into how we move, act, and learn. The podcast aims to expand an approach of thinking on the move and engage with the stuff of social and political and cultural concerns as materials that matter. This year's series, I will be talking to art and design researchers within the research cluster, Participate. nestled in the vibrant Leeds Art Research Centre at Leeds Beckett University and going wider than the Arts School to include researchers from other areas. Today we are speaking to Priscila Beni, who is a PhD candidate at the Federal University of Rio Grande do Sol, Brazil, in the Informatics in Education programme, also referred to as Computing and New Technologies in Education. She holds a master's degree in business administration with a focus on entrepreneurship and innovation and is doing her doctorate research in the overlooked area of neurodivergent adults. She has been visiting LBU to discuss her research with Dr Mark Fabry who works in this area. Today, we're venturing into a fascinating narrative around her research into how

self-knowledge about autistic traits can promote self-advocacy and inclusion by identifying strengths, weaknesses, opportunities, and threats related to these traits. In this episode, we'll discuss how inclusion is a process that begins with self-knowledge, followed by self-advocacy to meet our needs. Ultimately, she concludes, inclusion is a collaborative effort between us and our environment. Whether you're a postgraduate student, an academic, or a researcher, this discussion is tailored for you as we peel back the layers of this compelling research, igniting conversations on innovation, creativity, and the evolving landscape of art and design research. So grab your notebooks and settle in as we explore how our creative processes not only inform our practice, but also shape the very fabric of knowledge itself. Let's dive in. Is it Beni?

Priscila

Beni, yes.

Joanna

Beni, okay. Hello Priscila, very nice to have you on the podcast Thinking is Material. We have with us today Priscila Beni who is a PhD candidate at the Federal University of Rio Grande do Sol, Brazil. We've invited her here today because of a very interesting research, which is exploring self-knowledge about autistic traits and how they can promote self-advocacy and inclusion. But before we go any further, Priscila, can you just tell us a little bit about yourself before we even get into the research part?

Priscila

All right, so hello everyone, I'm Priscila. I'm from Brazil, PhD candidate. Let's say I'm on the spectrum. I was diagnosed when I was 21, but at that time the doctor just said to me, oh, you have like at the time I was Asperger's, he said, Oh, don't worry. You made-up, you got into the university and you have some friends. Don't care about this. Your main problem is ADHD. So I just forgot that information until my nephew was born. So from that point on, I think that I was someone just trying to adapt at birth. and survive in this world and then I had like some health issues and since then I've been trying to build my own my own identity based on who I am really am like being authentic so I'm in this process like stop masking camouflage stuff and trying to be myself like I used to be a really good uh let's say speech like yeah and and now after the burnout I feel like shy and all the time like introverted because it's from my nature let's say like this And so I'm this person that is building, constructing, developing her own identity through the spectrum.

Joanna

Your burnout, was this prior to you doing the PhD? Was it before your PhD?

Priscila

The first one was, the first one was, but the second one was in my first year. as a PhD student, yes. And I think because I had one in the past and then plus COVID issues like post COVID and one more burnout during the first year of PhD, like suffering some abuse from people like my ex-mentor and you know that was that led me to be in a high level of stress and then my body didn't handle anymore so I burned out again.

Joanna

So this is is this what you would call autistic burnout if we were looking at more sort of you know, maybe how doctors would phrase it, would they call it an autistic burnout or do you consider it it was just burnout?

Priscila

No, this was the kind of burnout that gives you the autistic individual regression. For neurotypical people, a burnout has some set of symptoms, but for autistic people it's pretty much different and even And even the doctors, the literature about, academic literature about is really rare. And if you go to the social media, forums, even some professionals, the rare professionals, at least in Brazil, that works with adults, we talk a lot about burnout. this kind of burnout that gives you some kind of regression, like you lose some skills. This was an important point on my presentation yesterday because everything, my search for answers about why I was struggling in life started because I knew that what I had wasn't just like issues, memory because I'm aging or you know, hormones or anxiety or depression. No, I knew that was something more. And when I started to look for it, I figured out that there is so a thousand people that had exactly the same things like we lost some skills that we developed during our lives and they just disappear because the your brain just really burned and since some things for us are not naturally it's not like the neurotypical people has some things, for example, they learn by instinct a social skill and autistic individual know. So after a burnout, you can lose those skills like just happened to me or you can lose some cognitive skills or you can lose some other many skills like it will depend on the person, but there are some people, for example, on Quora, you know, the some social media that people talk a lot, they chat like without, because your name doesn't appear, read it or Quora. So in my presentation, I listed some comments from people speaking about burnout in social media. For example, IT engineer mentioned that he got a burnout and he couldn't left the house for two years because he really lost his skills like skills that are really needed to take care of yourself by like going out. Another one just mentioned that he was or she used to be a successful scientist but then they got a burnout they lose so many skills that now he or she or they are living in the mother's basement at the age of 35 years old barely could barely being just able to take care of basic like but struggling to take care of basic needs. And once that you have this thing and you don't know what it is and why this is happening, because it's not written anywhere. It's not written in the academic literature. The doctors don't know about it. And we can't treat it. So we just got into a

dark, really dark, you know, moment. without support, without everything, just because of burnout. So many people are misdiagnosed.

Joanna

Okay.

Priscila

Like going to the doctor and they just said, oh, you have anxiety or depression, but instead it is a burnout because you can do things that you were able to do before, like really well.

Joanna

Okay, can I just go back a little bit to what this burnout looks like when it's happening. So we you know you've said about the loss or the regret a loss of skills and the regression that happens after a burnout but what what does an autistic burnout look like?

Priscila

It will depend on the person because, you know, the spectrum, it's a spectrum. So I have a set of traits. My friend, which is on the spectrum, has other set of traits. So a burnout can affect everyone in a different way. But let's say that basically we have some traits that are pattern like pretty much the same with with all of us for example the sensory issues about light lights or sounds or or like being like taking the things in a literal way like people say things to you and you really think that is like that So this is another trait that is common to almost all of us. So I can give an example among the traits. For example, the sensory issues. You used to handle being in places with, there is like some sort of people, for example, an office, and after the burnout, that light or sound that used to bother you a bit, but you could self-regulate somehow. After a burnout, you can't handle not even 10%. It's really hard because that skill that you learn or, you know, the way that you self-regulated before, you basically, that strategy is not enough after burnout.

Joanna

So the drop between coping and the tolerance level, that's a steep drop then, isn't it, through burnout? Maybe being able to tolerate some of those things, maybe being able to cope on another side of burnout, that causes it to go. So if I knew someone, with autism and they seemingly handled some things quite well, but they perhaps stopped wanting to do some of the things they've done before or they were withdrawing from some of those environments. Would that be a way of recognising that there may be a burnout happening?

Priscila

We must In this situation, I think that if you are considering whether it's a burnout or, for example, anxiety or depression, the line point will be if you don't want to do something, but you still can do it, but you just don't want to because you don't have the strain, you don't have dopamine, you don't have serotonin, you don't like, but you can, you can because You can. That's not burnout. An autistic burnout, like the words with regression, which is the one that's really hard on us. But if you try to do that thing and you don't do it because you can't in English is really can't not being able because you don't know how. That's a burnout. You don't know how you unlearned. I don't know if this word...

Joanna

Unlearned is a good word.

Priscila

Unlearned. I will give you an example. I will try to just literally translate it. But for example, when I met my boyfriend and we were talking online, for example, before we met in person, he was he told me that I like craft beer and I am right now I'm in a bar and I don't know I don't remember the name of the bar and he says oh I love this this place this beer like like oh I don't know the word to.

Joanna

The atmosphere.

Priscila

No no and he said something like it's because in Portuguese it makes sense but you know that word when you own a bar like you were like uh you own like you were the owner.

Joanna

Honoured or on?

Priscila

Yeah but in Portuguese there is an idiom like you said when you go to a place so often you like that place you use the word oh I own this place but you don't go there so often so it.

Joanna

Feels like home it doesn't feel a bit because it's familiar does it feel like home a bit because.

Priscila

Yes yes in Portuguese it has a meaning like oh I'm um I'm the owner like I'm the uh it was so social I'm just yeah okay but then I thought Why? Why is he? He's like he has a... Maybe I thought maybe he's an owner that just invests the money but doesn't work. And why? He works with computing. He's a professor. Why? But because in somewhere in my brain I just forgot that is an idiom. And I learned this idiom when I was a kid. And I just forgot because I took it literally.

Joanna

You know yeah yeah okay completely literally yeah.

Priscila

So I lost the capacity it was just I know I knew that idiom but now I take everything to the little way again.

Joanna

That's a very very subtle thing to suddenly find a small thing that you understand that you've learned and to suddenly find that you haven't understood it and then you feel you should know it because it is something you learned, but you, like you say, you've just unlearned it. So that's quite hard, isn't it? Because those are things that are not visible necessarily to everybody else around you. So you can be experiencing a loss or a regression and People around you may not know or be able to support you because it can be a very small...

Priscila

Even the individual can don't know what's going on.

Joanna

That's interesting.

Priscila

Many people don't know about the burnout, autistic burnout, only like some people on the spectrum that participate on social groups or have many friends or WhatsApp groups and social media because we support a lot with each other in the groups. So you heard about it, because you saw someone comment, then you can try to associate, oh, perhaps that's what I have, and you try to talk to someone that you know, that's what will happen to me. Because I only realized this was a burnout after I started to talk to people. on the spectrum that had a burnout or people some people that right now like they are my friends now but at the time they were just professionals that I found and they knew what was and it was really hard to find them and so you just think sometimes that you're getting crazy So I thought that it was getting crazy because I knew, for

example, to go somewhere and know that place is dangerous, like it has a high rate of violence in the city, for example. And I just didn't, you know... I forget about it. It's just... It's a kind of skill that you develop. Oh, this place is safe, this place is not. Like you develop this kind of skills, you know, and then they are gone. Another example would be, because this seems not to be so important, but they are, for example, since I work, I have always worked with people. I worked in like big companies, multinational companies, in marketing, a sales area, so I developed many social skills and I learned things about people, like when people are telling the truth or not, they are trying to convince you, you know that kind of malicious thing that in business perhaps you must have to figure out what's going on and you know this kind of thing it's a skill and this kind of skill like knowing if someone analogy if someone is being malicious with you or not I lost you So I was more vulnerable to be abused because I couldn't recognize the danger of being with people that are not really nice or they are taking advantage of me. So this is really dangerous. And sometimes you just not lose your social skills, but also the cognitive skills, for example, don't remember. you know you've been in a place so many times you just don't remember how to go to that place or uh you take so long to do something that you should do it in minutes and you can you don't know from where to start that's a burnout okay because it's really a regression like.

Joanna

So this is I mean, I think the way you've explained this is really helpful because you've actually opened up how this is a serious issue and one that's not very visible. And it's serious from, I guess, it's You know, never mind for the individual having regressions, it also means that other people might not spot that in others. But it also means the individual themselves might not see it, which leaves them very vulnerable.

Priscila

I think that you only start to see it when it's like in a high level, because When you really realize that you lost some things, that something is missed, just gone. Like something really important because maybe the small things like, for example, I used to, okay, I don't like salt or too much sugar on my food. When I am in someone else's house, for example, my mother, she used to add a lot of salt but since I don't go there so often like every day so I can handle and now I can't handle anymore because it's too sensitive and also in a place with a lot of noise and not be bothered for example like I don't I There is something that autistic, many autistic people has that you can follow parallel conversations because you don't know which conversations should follow. So to put a group of more than, you know, five people, it's too much. But since I worked many years in social areas and I teach also at the university and so I handled this I used to handle this very well, but now I can't.

Joanna

Yeah.

Priscila

I can't. I developed some ways, like quick way, like, okay, there's more people here than I, that I use, that supposed to be, but it's something that you don't think about, oh, I will handle. You know, it's quick and fast because you can do it. yeah because you developed it and now I can't again.

Joanna

Okay so um that brings us to your research then it completely makes sense why you are researching this um so um and can you tell us a little bit how you're researching this issue?

Priscila

Actually my research is more about the autistic hidden traits uh okay yeah there but I I end up in the straits because I was really wondering why we struggle struggling so much in the adult life. And then I figure out like a process. Oh, you age and then you lose your like some skills or some strategy are not enough anymore, and your health start to deteriorate with time. And also when you age, you have more responsibilities, so more pressure, stress, anxiety. And then you have, for example, if you're not working in a friendly environment with nice people, not doing what you like, or so many other variables, and then you have a burnout. And then the co-occurring conditions like it's conditions that autistic people has a predisposition to have, for example, depression, anxiety, panic attacks, things like that, that they just appear. And it's, it's, it becomes something that was small, just It's just something big now and you start struggling like one after another and people lose their jobs, their relationships and everything. So I was wondering because I was struggling why I can do this again. Like I used to write a paper in a week, a really good paper because I'm such a good writer and I can't do it anymore. Why? looking for the answers and talking to people, reading people's comments, I figured out that no, the autistic, being autistic must be more than the things that are on the literature about autism. I mean the DSM, which is the is the the Bible of the magical. you know that it's a manual to describe the mental health, mental problems like neurodevelopmental disorders are there. When a doctor, if you go a consult and you have depression, the doctor will use the DSM criteria to diagnose you. So that's is the Bible and when you got that Bible you see some autistic traits they really make sense but I thought this is not enough to give us this struggling this is not enough.

Joanna

Okay so it's got very big gaps um that you yourself have experienced and you're you're looking at that list and you know it's just not even It's not explaining the full story.



Priscila

Yeah, it's not just that. And also the lack of support because many professionals, let's say clinicians, and they don't know autism at all. And even worse, they don't know anything about autism in adulthood. Yeah, it's something it's really bad today, let's say. it's urged for solutions and answers because they really they don't know. The focus, all the focus during decades in Alte's research is about the childhood. But we grow up and we have some the same issues if we didn't have support. So what happened?

Joanna

Yeah, in this country we have, sorry, I didn't mean to interrupt, you're just making me understand there's a system for support of children with mental health issues called CAMHS. I can't remember what that stands for, but basically kids that may be diagnosed with autism might go through that process. They may receive some support, but at 18 there's a cut off, at 18 that ends. and all that happens is they get told to make a phone call and you can talk to someone on a phone when you need to and all the responsibility for coping with all those things suddenly falls on you which of course that that's it's kind of a ridiculous thing to ask them to do because not everybody with autism is ever going to just pick up a phone and phone a number and say I need I need some help and support now and so yes I can see why 18 year olds and plus they're just abandoned in an adult system of life with without proper support.

Priscila

Yeah we have two problems there first of all It's out without is ASD doesn't have a cue, so it's lifelong caring. But no one, this is just a term, a word that I just made-up, but lifelong caring.

Joanna

I love it.

Priscila

And we had that and we got. And the second issue, which is something that relates to my study, is that All the support and assessments that are made in this kind of support, like for example, this department, we have one in Brazil too, but really, it's still in the beginning, you know, but I think that many countries, they have this, but the problem is they develop, they create the support based on the researches based on the magical literature. And the magical literature is about the DSM. So since the DSM only lists, let's say 60% of our traits, it's not everything there. We can, people can think about ideas to give us support for some traits that we might need. For example, not some social skill to deal with anxiety or when you are in public or things like that. They just ignore. They are really, they, because they don't know the policy maker. Those people that made the

strategy, they don't know because it's a gap. That's a gap that I found, like I found hidden traits, going, diving into the classical literature on autism, which means the classical, classical, the pioneers, which are Grunia Sukraevo, Hans Asperger and Leo Kerner. OK, I listed more than 200 traits and these traits are not in DSN. So yeah, and when I so.

Joanna

So can I just recap that? Are you so first of all, I loved your phrase magical literature. This idea that the magical literature that we base all our strategies for support on is actually not so magical because it's got huge gaps in it but you're saying that some of those gaps might have been there if we'd attended to the Pioneers and their 200 traits list more if we'd paid attention to that.

Priscila

Exactly when I when I finished the first part of my my let's say, revising this literature and the first analysis, my first thought was, oh, I have to tell the world this is wrong. I have to tell to the DSM they are wrong. But I thought, I am not on the health science. I am no one in this field. And I can't really, as being an autistic person, I can't really wait for them to realize that it has more that has been hiding and they should look it carefully and add the traits on the DSM because they really could help to diagnose adults that are unrecognized as autistic and also help to develop better interventions and treatments. and I decided that I am I will not be that person because I'm not from this field and what I do it's something that can help people to assess these traits to acknowledge these traits and to check if whether they have an impact a negative impact in their lives and if they have to figure out how to how to to improve like what, how to get the specific needs. I will give you an example. Yesterday on the presentation we did a really nice activity about because the things that these amazing researchers Kaner, Asperger and Tsukrajeva, they listed, because they followed their kids, like the sample, hundreds. Each one of them had hundreds of kids in their hospital schools that they followed since they were three, four years old, until they got the adulthood life. Even some, almost 40 years old.

Joanna

Wow, that's a huge durational study, isn't it? That's a huge, that's a lifetime study, isn't it?

Priscila

Yeah, but Grunia Sokhrajevo, unfortunately, she was only acknowledged in the west side of the world recently, actually. when her first paper was translated into English it didn't get the impact that tooth have. So in the last three or four years some researchers are shedding the light of her work and also Asperger's it has some other papers or notes

that he left about the kids that he diagnosed as autism pathology, the name that Asperger gave. But it's there, it's written and no one is looking. For example, a trait that really is important in adult in adulthood. The three pioneers listed that the kids they were observing, they are pedantic. Being pedantic is not a nice thing.

Joanna

Why?

Priscila

Because we have some rigid brains Sometimes we can't see only white and black. We can't see the gray, especially if no one taught us to see the gray if we didn't have the support. We grew up, we grow up seeing black and white. So we are really honest. It's one of autistic people's strength is to be honest. And another thing is to be really rational, like we have this part of our brain really well developed the rational part the neurocortex part whereas we have like some let's say problems in the limbic part that controls the emotion. So the problem is you are very intelligent like here rational but your emotions doesn't come out the way you're supposed to be. But being a pedantic person in childhood will be that kids that will be called as a spoil or overreacting or just annoying kids but in adult life this could be the person that is judgmental the person that always wants things the way they like and they they can't really see another way to do things because like Sometimes you only see that way because it's the way you think is more rational, that it's the right way. It could be the, let's say, the right way, but things in the world are not black and white. You have the gray, you have each person. feels and see the words in different ways. So when you were pedantic on your values, your principles, it could be a nice thing if you have good values or principles but if you don't or being pedantic and doing things like if someone says oh This is not healthy. You shouldn't eat that. Oh, all right. But only on Saturdays I will eat. But no, it's not healthy. And you will be sick because of it. You can't. You know that you can't. The doctor said, don't take it.

Joanna

So they become very absolute.

Priscila

Yeah. So that person will be the person that people don't want to be close with. That you don't know your heart. For example, in the workplace environment where people are competing and also colleagues that is difficult to make friends, like really good friendships, people will call you. It will stereotype you like that person that, you know, it's not good so also in social uh like we just met at the university we are colleagues I'm a professor here too and we just met you don't know my heart you don't know I'm a good person I have good values I'm kind yeah and I we just met just because we are really

honest which is another trait that you have that you can't like be that honest all the time because people sometimes don't want to listen the truth. It's just just to have some support, you know, just to say, oh, I have my hair cut. but did you like it? Oh yes, yes, just you know...

Joanna

So no tact, no tact, no social...

Priscila

Maybe if you were authentic you just say oh but and oh yeah you know you went to that salon hair again and you knew that is not good. You need to take charge of high price but and they don't do like a nice work so supposing that you said oh I think I didn't like my new hair or my new you know I didn't like this the results instead of supporting no it's nice because that's what friends do you just will turn it on your traits being honest because just no one taught you that in social skill like in social environment you should just give people some support and you will you will be pedantic I say no you should have gone to the salon where that I gave to you the address why did you go to the other place you knew?

Joanna

There okay so that's yeah brutal honesty, as we might call it. So I'm just wondering, Priscila, then, in terms of you're wanting to reveal more of these traits in your research. And I guess I'm curious now because you said you were going to be researching and working. I thought you were going to be working with groups. or with people about this generating more self-knowledge so people can have more people with autism can have more advocacy for themselves and that self-knowledge will help them. So can you tell me a little bit about how you're going about that?

Priscila

This will be the the final result if my study proves that if you you acknowledge this kind of traits that yeah the literature like being pedantic and you acknowledge that and you can see oh my god I didn't know that I I didn't know I do this and this is bad because no one taught me so what I'm doing now that I figured out all these traits and listed and I will try to develop let's say a technological tool where people can access to through social stories stories just like this one but how lovely in a nice neutral and inclusive way yeah to so the autistic individual will answer some after reading the stories, answer some questions like say, oh, this happened. Have you ever seen you in this kind of situation? If yes, how frequent? And then the the tool will work like the mathematical and programming part will give you a SWOT matrix of your traits like after you. read many stories social stories yeah you answer how frequent these traits are in your life the tool will give you a SWOT listing listing listed your your strengths like one side your

strengths the other side some weaknesses And they decide weaknesses that if they are like, if you work on that, it can become a strain, like the hyperfocus. And some are some traits that that are threat and you need help, like help you can figure out yourself. You you need like intervention, like a doctor, psychologist, someone to help. So I think that once that you know, you have your SWOT profile, you can start work on what you need to start to not being epedantic.

Joanna

There's two things that you've said like that that I just want to pick up on. One is this use of stories and examples for people to learn to recognize their traits. I think that's rather beautiful because as I've been listening to you, I was just thinking to myself, this podcast has a flavor of stories and I've learned a lot about traits, their impact, how they can be misunderstood, how they can be missed, how they can be missed by the person themselves and others and all of these things but you've done it through this very lovely unfolding story, example, story, example and that has flowed really nicely but provided so much knowledge so I think that's a lovely thing to test, to see how people respond and go, ah, yeah, I recognise myself in that story. I think that's very interesting. And then the second thing I guess I wanted to ask after that observation is, have you got, how will you test this will you invite people will you be working alongside specific people?

Priscila

No we are um I say we because it's my PhD thesis but I am not on my own okay so many people helping uh aside from my supervisor in Brazil I have people uh like uh mathematician that he's going to help with the mathematical modeling and he's also on the spectrum. I have two neurologist doctors, one is specialized in autism in adulthood, actually the only one in Brazil that works with that, he's really interesting. interested in my research and another one is Liz she's a occupational therapist and on the spectrum and she works with adults too and she also works with neuroscience so each step of my research they will help like actually they are helping already like to figure out the social stories the traits that really matters because yeah I summarize them in 90 but I we still think that it's too much perhaps we have to summarize a little bit more and after we finish the like the social stories and also I will test some autistic adults to to help uh you know it's really valid the social story I will test this and after this is ready I will ask for experts on autism in adulthood, hopefully some people from the UK, since I got some help in Leeds Beckett University. And when the, let's say, this research tool instrument is done, we will put all the information ads in a technological tool. It will be like an assist, technology or something like that and invites autistic adults to test to read the social stories and to answer the questions and after that there is one more step which I think is the most important because it's the like the final end because the thing is we need we don't we say We don't have support, right? So we started talking about burnout and everything else. We don't have support. And we don't have support not just

because the systems are broken or they fail, but also because nobody knows about these traits and how these traits impact in our lives, impact our lives, like in us to be struggling. And so I thought, Since we can't wait anymore, if we acknowledge these traits, but after acknowledge, for example, a flat, oh, I'm pedantic, I'm a pedantic person, what should I do? So you can't just change.

Joanna

No, you can't turn that off.

Priscila

Yeah, you have to work on that. So we ask the research sample, the research individuals, to um to think about what they need what are the what uh let's say in the first person with it's easier for me so what uh do I need to have my needs of uh being pedantic uh like uh What do I need? What do I have to do to improve this trait? Like, what can I do to help myself to stop being like that? Since it's because people say, oh, it's just someone that is not polite, but it's not that it's impulsive because it is neurological. You know, there's something related to the narrow thing like it's impulse, you know, is impulse and you have to control that impulse. So the first part people will ask to think about their traits. Oh, what do I have to do to stop being pedante? And then the person will have to answer what can I ask for the other people, the people from the environments that I am in, for example, my friends, each one will have like a space, like at the workplace, at my house with my romantic partner, with my friends and my family in the academy, school, you know, academical places. What do I need? from the other people to help me with this trait. And then the final question will be, what you have and what you think the other people can do, it's enough? If the answer is no, you must think about what else do you need.

Joanna

Yeah.

Priscila

And after that, I will interview people and get their perceptions about this. But I will not interview them right away. I will like for, I don't know, two or three months. So they can use this tool. They can use the final report because after that it will have a final report. So they can use this final report in their lives. And then I want to interview and know. Acknowledging these traits, they feel more confident or self-advocate for their job. For example, we are friends. I say, oh, look, sometimes, you know, I'm really pedantic, but I'm trying to work on the traits. Would you help me? And you will say, oh, how can I help you? Say, just being patient and call my attention when I am like passing the limits and we work on, we can negotiate. So I want to know if people talk to other people, if they self-advocate and if they don't, why? What difficulties they faced and what barriers they

found or if they think it was easy or it was nice and if this self-advocacy increases the level of not like thinking that one day you can be, you can achieve autonomy, which autonomy in the philosophical sense that you can be yourself, express yourself with authenticity, being respectful with people, being respectful with yourself, within no moral social rules, because we live in cultures.

Joanna

So I'm just going back a few paces because there's, you know, there's a lot to take in there. There's certainly several phases to your research and it sounds like your team are going to be brilliant at testing and trying things out, but you've then got this next stage where you're actually giving people the space and room to try out this and to reflect on and you gather information of, I guess it's not so much whether it's made them feel more confident, but in what ways does it support them? And if it doesn't, what, you know, why not? What are the obstacles? What's stopping them from actually having that autonomy to say or ask and I you know obviously this is you know an amazing bit of research because it goes far beyond a lot of the sort of diagnostic tools that we have for these things now that give a diagnosis or they might point people to different things that they can help themselves with but if those, like you say, those strategies are missing, most of the understanding to do with those traits, they're just not going to be helpful. So there's a huge gap. There's a huge gap. But what I particularly like about what you're doing is how you're not just researching how to develop this tool, but you're actually really investing time into measuring the impact of it. And I think that's an area that can get glossed over. We can race, you know, as researchers, we can race towards and get a little bit of impact and go, hooray, it's wonderful, and this has worked and this has worked, but there's an integrity to the time duration and how you're gathering your responses from people participating with the software or whatever learning strategies they find to find out in what way it does help. Because I think, well, just from things that I've come across, I think two words that I hear frequently for people with struggling with autism in adulthood is autonomy. And I'm not sure sometimes whether autonomy is understood by others enough of what is meant by that. Because autonomy is not just looking after oneself, it is self-expression, assertiveness or asking and all of those things. So I think that's a crucial part of this. Yeah.

Priscila

I think that, for example, in the Kantian, like the Emmanuel Kant's way will be like, which is a philosopher I like a lot, it's like you'll be able to have a decent life. So someone to have this in order to have a decent life must have a job, a vocational career. that you must have you must be able to pay your bills you must be able to raise your family if you want to have a family or to achieve your goals in life respecting others and respecting yourselves for example the guy or girl or there I don't know the person that's mentioned in social media that they have he or she, they had a burnout and after that they in the

age of 35 years old and used to be a successful scientist and now is living in his mother's basement. This is not autonomy. And the other one, for two years in his house, the IT engineer, this is not autonomy. Autonomy means to me I'm not talking about like the physical condition like I know I'm talking about being able to to have a girlfriend or a boyfriend because you learn from social skills you know being able to be with some friends in the environments that you don't really care about uh the soccer game but you like to be with your friends and that's okay when they are talking about soccer game you are on your phone it's just because you know things like that because they matter because in the end if you don't have people if you are only by yourself, you have only your parents. When they die, you will think about suicide. That's why the suicide started to come into the light when some of the medical communities started to see that many Asperger people were committing suicide after their parents died like after why this was happening just because your parents are like the people that really loves you more than anything the world they just accept you the way you are but after that you lose that support the only people that really understands you and not judge you you are alone because you struggle you struggle you have a marriage and you you get divorced and your kids don't like you and The first thing is not worth, this life is not worth living because you are alone, you have so many health, mental health issues and you're not as good in your job as you used to be. So that little things, you sum and plus one and more and more and more and then you think about suicide. Like six in ten people on the spectrum think about suicide. They have suicidal thoughts and three in 10 really try to kill them. So it's a really high number, really high number.

Joanna

So you're actually, this research has a larger remit because it is about putting into place something that has the opportunity to support learning after a burnout and learning some skills within adulthood that might mitigate against these more extreme crisis points that people might experience. I find it interesting because, I mean, the journey of this piece of research has got, obviously, A long way to go, but it seems like there's, now that it's now that it's happening, there's got a lot of possibility to it, because, of course, if you develop this as a learning... tool and you had more people engaged and there were some aspects of it that were effective, then it's how do you share that, how do you share that in different languages and in all of these aspects and of course I'm really aware that every country, every region and every culture has very different responses and obviously you're not trying to answer sort of all people with autism and autonomy everywhere. But I can just see this opens up a huge area of new research to take place in terms of seriously attending to strategies and needs that are fundamentally more effective. um for for people who need support um and I can't believe it's been missing for so long.

Priscila



Yeah I think that it's just I don't judge because science evolves in in different paths sometimes um uh back going back that time they were really uh worried about the the kids about why there are so many kids on the spectrum. So I think there are many research in different fields, but I think we have a lot of information that can help. People to do applied research, and that's why I'm that's why I came here, because here in the U.K. I have seen many people doing applied research.

Joanna

Yes.

Priscila

This is really important because we can no longer wait for support for things going to the theory and then... And then... becomes practical. It takes years! No.

Joanna

Too long.

Priscila

We need that help because we don't want to die. So here I've seen so many people like Professor Fabrik is doing a brilliant research on autism at the university. Professor Love works on projects on architecture and nice designs to neurodiversity people. That's right. You know, in spaces that are not friendly. This is all applied research. And I think that with if we like just give hands with the information that we have already about autism and stop seeing what is really not really important to those who are trying to kill themselves right now. And we will find good solutions. But the thing is, what I have seen so far, these people that are looking for solutions or people that, oh, well, are they're autistic? or they have relatives on the spectrum, or they have really close friends on the spectrum, and they can't wait no longer. They came a long way, it's that. And so I really want to call attention for those who want to do research on autism, just try to connect the dots about things, because there is.

Joanna

Yeah.

Priscila

A big amount of literature over there, just trying to find the gap and propose a solution.

Joanna

I think, I mean, we're coming to sort of the end of our time, but I really like the way you've brought us to that point of who it is and why we're motivated to do that kind of research, but also how you are putting out a sense of urgency about the need for this

research. I really appreciate that and the need for action and applied research now. I think that's a really important point to end on. But I also, can I just thank you for... I guess explaining so beautifully where that research has come from, the gap in the research, your research methods of the way you're working with people and where you're placing that and the whole picture of where you want this to go. You've given such a lovely, comprehensive narrative to what is both fueling this, both personally and politically, which I really appreciate. But something that I didn't expect out of this podcast is the strength of the storytelling, which has really come across, and just the power of the message that you've got to say. which I think is beautiful. And I kind of, I want to end the podcast there because it's kind of a call to attention for us all to, all to be aware of, but also in seeking out that highly tuned observation that you've brought here today on looking for those gaps in research in these very, very difficult areas. where people are baffled and perhaps don't know what to do. So I just want to say thank you. I've thoroughly enjoyed listening to you. I can't thank you enough, it's been great.

Priscila

Oh, thank you for inviting me to do it and thank you very much. I hope to come back soon. perhaps come back. I will try to do one part of the research here, like trying to have some autistic people here to test to. So I really, we work hard to get another chance to come back here to do that too.

Joanna

I would love to chat to you about that once you've done that. I would love a follow up and to just ask how that went. I think that would be really lovely. So yeah, do keep in touch and let us know how you're getting on. I think your insights have been very pertinent and very important in the times we're living in where there's more statistics than ever. talking about the impact and and some terrible impacts to do to do with neurodiverse issues. So yeah, thank you again. And please do come back.

Priscila

Welcoming people Liz are really welcome, welcome, welcome.