### Kelly Bron Johnson (00:00):

Welcome to episode number eight of intersections on the spectrum podcast. The intersections on the spectrum podcast is the brainchild of Doug Blecher and Kelly Bron Johnson created to discuss intersectional issues within the autistic community and give visability to commonly marginalized, repressed, underrepresented, or erased identities and issues. We aim to introduce you to the people and stories you didn't know about, but needed to hear and hope that by seeing yourself represented in the community, allows you to feel seen .

# Doug Blecher (<u>00:31</u>):

Today. We are joined by Maisie Soetantyo an openly autistic family coach, advocate, and professional trainer. Maisie, t.hanks so much for joining us.

### Maisie Soetantyo (00:43):

Thank you so much for having me. I mean, it's, it's always nice to be invited to talk about things that I'm very passionate about. Thank you for having me.

# Doug Blecher (00:53):

We all have multiple identities. So for you, what would you say are the identities that describe you?

# Maisie Soetantyo (01:03):

I think, uh, first thing I always say that I am autistic and it's even though I was, uh, diagnosed very, very late, uh, as an adult recently. And I'm very proud to say that I'm autistic. So that's the first thing that would come out of my mouth. And I'm so lucky then I'm able to do that because my family loves me no matter what they are my game-changers my parents. Um, my mom was a game changer for me, even though, you know, she didn't know when I was a little girl, there was no such a thing as getting a diagnosis or, you know, occupational therapy or, you know, we just had, uh, our parents and maybe some tutoring and that's it, you know? So, uh, I, that's what I say in my family ever since I was a little girl, I think having a neurodivergent has always been part of our family identity and family culture.

## Maisie Soetantyo (02:17):

I had a non-speaking autistic aunt who has down syndrome. And so I think it's just part of our lives, you know, understanding, trying to communicate and connect with somebody who is different. And I think in our family, we just have more Neurodivergent than typicals. So it's actually kind of cool.

#### Kelly Bron Johnson (02:45):

I want to, I guess, jump onto that topic of diagnosis. So talk about your process of getting diagnosed and especially if you could give some advice to adults who are trying to get diagnosed as well.

## Maisie Soetantyo (02:59):

Yeah. I think that's a good question. I was asked the other day about being self-diagnosed. Is that a good thing or not enough for someone? So I can only speak with my, through my own personal experiences. Obviously there's something about autism that really has drawn me into this field. I, this is my work for like over 30 years now.

#### Maisie Soetantyo (03:25):

It's been a long time. Right. And I, um, came across the field of autism at UCLA and I started working with autistic kids doing behavioral intervention. And I think because I am autistic, I kind of intuitively I intuitively sensed that this is not right, like doing all this teaching, these kids rewarding them to be able to learn and seem to make gains according to neuro-typical standards. I just didn't know at that point exactly what was wrong with it. So I kept getting trained in the field, leaving it behind, trying something else. All in the context of working with autistic kids, knowing that it's, there has to be something better, you know? And so having done this for 30 years, my little autistic clients grew up, they still cannot get a job, a summer job at Domino's pizza, even though they make pizza almost like every other day or every day that the pizza expert, but they fail because they did not pass the verbal interview.

## Maisie Soetantyo (04:40):

So I was thinking, you know, for people who have a diagnosis ever since they were little and with all these therapies, I think autistic kids are the hardest working people on this earth. Honestly, honestly, school therapies, you know, I try always trying to catch up and also parents, uh, really trying to the best that they can to prepare their autistic loved ones with the diagnosis to really, uh, get ready to be part of a community and get a job or whatever. It's still not enough. You know? And so I think when you asked me about the process of getting a diagnosis or just maintaining a self-diagnosis, I think it's a personal preference. Uh, I think for me, I knew like in 2019, when I started connecting and researching for employability, I talked to so many autistic adults and quite often they are the ones who would say at the end of our chat, they will say, are you sure you aren't autistic youfself? You know, and I started thinking, Oh, well, yeah, I guess I could see how you would think about that.

# Maisie Soetantyo (05:54):

And, you know, um, also through my kids, my son, and exploring his neurodivergence, so many, many parents today, they're discovering their neuro differences alongside their autistic family members. So I would definitely suggest that if it's important, for whatever personal reason, go get a formal diagnosis, if you can find somebody who can diagnose you, uh, I think it has given me peace and really giving me my own personal toolbox to really embrace the sensory differences and setting up boundaries, unmasking, which actually gives me, I think, more energy and focus to be able to do my advocacy. You know? So I think in that sense, it's really important to get to just whether you go through the formal diagnosis or not to really embrace it, it, you know, if you know that you're autistic then just like own, own itonly means embrace the hard days in embrace how certain things are really hard because of your sensory differences embrace that, Oh, you don't feel like going to a costume party because the costume is itchy and who cares if people tell you you're a party pooper, you know, that's fine. You know, so this is, it kind of gives me the validation that I need that I, and then it helps me to be able to explain to people better, you know, instead of saying, no, I don't feel like joining your party, you know, but I can say, this is the reason why, yeah. Does that answer your question?

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Kelly Bron Johnson (07:38):
No, it sounds great.

Maisie Soetantyo (07:39):
I always go the round and about,

Kelly Bron Johnson (07:44):
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Well, I especially like how you said for you, it brought you peace, you know, and that says to me there's so much power to that. Uh, you know, just saying, I have peace in this. I have a comfort in this identity. Um, and that, to me again, if people are able to get a formal diagnosis, it's not easy to access, it's expensive, but if they can, and just like you said, have this sense, of piece have this sense of acceptance.

## Maisie Soetantyo (08:10):

I think my husband actually said, well, I knew you were autistic like a year after we started dating. I knew it. I was like, how come you didn't say anything? And he said, well, I, I don't think you want to hear, you know, how people want to hear what they want to hear and when they're not ready, they will just push it back and say, no, that's not me. You know? And it's so weird that I been in this field for so long and I never really connected or like all these autistic traits to myself, but post-diagnosis, I would just walk around and think back about past personal relationships or my dad, and my grandma. I'm like, Oh yeah, aha. You know, no wonder so many broken relationships and family dynamics because you know of the mix of like neuro-typical and neurodivergent in the family. So it all makes sense to me, you know? And yeah. So that's, it has come full circle for me,

## Doug Blecher (09:18):

Something really cool that you're a part of Maisie is, is the very first Indonesian autistic led neuro diversity paradigm conference. Can you talk a little bit about the importance of that conference and how can people go about, uh, registering?

## Maisie Soetantyo (09:37):

Thank you for spotlighting that event. It's very, very important because this is the first one that is totally autistic lked. We, of course, we've had many, many conferences and trainings for, uh, neuro-typical adults, uh, working with special needs individuals of all types of diagnosis. But this is the first one that, uh, I'm able to organize and put together with three other autistic adults who are out openly about their diagnosis. And that is very, very rare in my country is very rare because everybody likes to hide because of the stigma. And, you know, um, I think also for Asian culture, it's very hard to admit publicly that you are struggling with the diagnosis and trying to figure out how to raise, you know, someone who's different than you and people still tend to like to keep it under, under, you know, just hush hush. And I really believe that, uh, the world is actually not ready for autistic people and for neurodivergence because the, the implementation of full inclusivity at workplace, it's still very, very early in its development.

## Maisie Soetantyo (11:08):

And if we, as parents, we don't know the how to advocate for our artistic family member and speak to truth without using functional labels that, uh, this problem will continue in five years, 10 years, that rate of hiring of neurodivergent people will continue to be slow because it's just human beings. If you're not comfortable, if you don't know about the subject matter, it gets awkward. You know, you, you, you're afraid to ask questions. Definitely you're thinking, well, you know, I, I'm not equipped to hire an autistic person. It looks like it's just going to need tremendous amount of my time. My staff's time to be able to include, uh, an ADHD or autistic person or non-speaking person into our, uh, company culture. So I really believe that step one is really educating parents of neurodivergent kids to really understand what is autism, you know, is a subculture its a neurotype. It's a different engine. It's an different information. Processing is not last. It's not a lesser model. It's a different model. It's like talking about apples and oranges, you know, or a tablet talking about a Microsoft computer versus an Apple computer. It's a

different engine it's differently built, but both as valid. And what we need to do is come up with a different manual.

## Kelly Bron Johnson (12:47):

I really liked that from, uh, abolitionist approach, you know, like I think the systems are broken and we need to really to break the system that have caused a lot of these inequities in the first place. Right. And then we can start to bring in people, you know, from the spirit of equity.

## Maisie Soetantyo (13:03):

Right, right, right. So I'm very fortunate for this upcoming conference for Indonesia. Of course, I have to do it in my own native language, which is, I'm very deathly afraid because I, I, uh, haven't spoken in my native language for a long time. And all of these terms, you know, it's kind of hard to explain. It's really hard to translate, but I think it's going to be great because I think we're very passionate about sharing our truth and our journey and our, including our struggles. And Gita Sjahrir is a very, um, she is a brilliant, brilliant business woman in Asia, very well known. And, um, she was educated here in America and she talked about her selective mutism for years and years as a way to protect herself in mask while she was in school. And she talked about the bullies, actually the bullying came or happened to her because of her teacher's perception of her as a non-speaking, you know, and that's why it's such an amazing sharing to have somebody who is so successful like Gita, and be able to share this openly for our Indonesian parents in communities.

## Maisie Soetantyo (14:30):

I think it's huge and Yoshosa loves. He loves to talk about his, uh, school experiences, you know, going to college, uh, and thriving in that environment. Uh, so that's what he's going to talk in. Uh, and, uh, Julie Putra is another openly autistic lecturer and artist. So she loves to talk about art and how it's such a great medium of, for special interests, how that really gives you a safe zone and how to nurture that. So, you know, it's just, I know it's just for people, but I think we are going to capture very important topics to really give people a good, different mindset, plant seeds. Yeah. So if anyone, if you speak Indonesian, you know, you can, um, register on my Facebook page and also on Instagram, my Instagram account at autism career pathways, as we get closer, I'll post the link and people can register.

### Kelly Bron Johnson (15:36):

Um, I want to talk about masking a bit because you know what it up, and even before recording, we were talking about masks just to give context to anybody who doesn't know what masking is. Uh, this is basically when autistic people kind of feel that they have to almost wear a persona or a mask to fit in. Then this helps keeps us safe from bullying and judgment and that kind of stuff. So recently you created a video series on why and how children mask. So what are some of the reasons that children start to mask and what can parents do to support their children?

## Maisie Soetantyo (16:09):

Well, I think when you are a child, you are still trying to figure out who you are. And, um, when you are a child, your mirror, like how do you develop that stuff? Identity is through how, how adults actually perceive you, right? And when you think about autistic children, and especially if you're in America, you know, the moment that formal diagnosis is given to this child, then your life is turned upside down because of the amount of therapy that you're going to have to go through. And pretty much, you're not a kid anymore. You're going to be an over-scheduled kid because of your autism diagnosis. And you will

have therapists coming to your home. And of course the recommendation for in-home therapy is a minimum of 20 to 40 hours of therapy. And, you know, and then you still have to do speech therapy and occupational therapy, social skills therapy.

### Maisie Soetantyo (17:27):

And on top of that school, I honestly, I don't know how an autistic kid would survive that. I struggle with more than two or three zoom meetings. Like I just really, I pay for it in the evenings, you know, where I would just tell my families, Oh, I'm so sorry. I just can't. I just have to switch it up. I just can't speak it. I just don't have it in my brain anymore, too. I don't have any more output. You know? So this is the issue with how autism or being different is perceived. I think in many, many Western countries that it becomes, uh, you no longer see the child as a person who's very capable and who's still developing, but you look at this person as a deficit model pathology model, and it becomes about taking data about this person based on this person's performance and not taking into account when you're autistic and you have sensory differences, what you're able to do every day, your output is going to vary because we're dealing with sensory burnout.

## Maisie Soetantyo (18:45):

We're dealing with, you know, sensory overload. Uh, and most people don't even think about that. You know, if you're a therapist, you're a parent, you're not aware of it because, uh, it's not considered and discussed as part of the school goals or therapy goals, you know, because all the goals are created to make this person seem like I'm ready to learn in front of you meaning I can sit in front of you and look at you, use my eye contact so that, uh, I can look at the photo. You show me and respond correctly and forgetting that autistic people, contexts is not really, it's not something that we naturally are wired to pick up. You know? So if you show a kid, an autistic kid, a picture of an Apple, that kid would not necessarily know a green Apple is also an Apple. The drawing of an Apple is also an Apple or at the supermarket.

#### Maisie Soetantyo (19:49):

I see bunch of apples. Oh yeah. I know that those are apples, you know, because it's being taught in a such a specific way, without context. It's just by repetition and the reward dangling the right carrot in front of this kid. You know, this just all like the beginnings of masking. Like if you're an autistic kid, you have very minimum of understanding that, uh, this is why I am as an autistic person. I need to hand flap to reset. Or I really liked to play on the iPad as a way to calm down. You know, it's still developing and you don't know what you don't know. And then you're constantly being expected to perform with rewards by adults who don't understand, neurodiversity paradigm and sensory differences are not considered. You know, it's like a sticky note. You just put it on that kid, yellow for this, red for this, right.

#### Maisie Soetantyo (21:03):

And then, um, all the little pleasures that a kid might have, you know, it's being withheld, unless you respond correctly, what is, that's not life, how you just define, as you have to do eight out of 10, 10 out of 10 otherwise this program will not be updated because you have not met the data that we want. It's every time I see this, it just breaks my heart in little pieces, because this is the beginning of masking teaching, small children who are still very much developing their own identity sense of self into a model defined by neurotypicals. Right? And I'm talking about well-intentioned people I'm never ever saying that autistic kids should not get therapy, not at all, you know, but the mindset behind this it's I think a

lot of clinicians and therapists and teachers, they're not aware of how they should learn from autistic adults.

# Maisie Soetantyo (22:25):

First of all, know about masking. Know about what are the signs when little kids mask, they they're different from each person, like how they perform differently. It depends on the carrot You have. It depends on the adult you have, and masking for little children is a survival mode because a lot of times they just they're like a Rolodex, right. They're trying to memorize, okay. If I see this picture, this is what I'm going to say. I see this teacher, like this teacher has very anxious energy, so I need better detail, like zip it and sit straight because I'm never going to get this picture done because this teacher will tell me sit straight, hands quiet, you know, uh, look it's picture, you know, like it's just never ending. This is not a childhood. It doesn't matter whether you're autistic or not. That is not a childhood

# Doug Blecher (23:25):

Maisie, Do you have, do you have some recommendations for teachers, maybe mostly neuro-typical teachers in terms of learning? Is it just as simple as listening to podcasts like this going through the openly autistic and actually, autistic hashtags, or do you have any other suggestions for them?

# Maisie Soetantyo (23:46):

That is a really good question, Doug. I think I worked very hard in my advocacy through Instagram. So I run two Instagram accounts, the parenting parenting, and for clinicians and educators is at Maisie Soetantyo. And I just try to be in the middle in a smart way in the middle, meaning I translate to the autism community, the neurotypicals community, just, just trying to translate about masking, unmasking, how to know these subtle signs, how to support your children to unmask and be themselves, you know, how to let go of your standards and really understand that good enough for autistic kids and autistic people. Uh, it's different, you know? Uh, but yeah, so I think, um, they didn't come on to my Instagram, uh, account. They're also accounts, uh, like on Facebook noneurodiversity nurturing neurodiversity. So that's a really safe place for parents to upload their videos.

#### Maisie Soetantyo (24:59):

It's a closed video and it's just a platform to really learn read together exchange videos, exchange ideas. And it's so amazing to just to see these kids just thrive and blossom under just, just at home, being with their parents, you know, autism itself doesn't need treatment, right. And want to make that very clear. So for people who listen later, autism itself doesn't need therapy but the co occurring conditions that come with being autistic for some people that needs to be addressed. So I'm talking about Apraxia if you have dyslexia on top of that, if you have depression, if you have, uh, yeah. All these other things, if you can find a neurodiversity affirmative, therapist to help you. That's ideal because if you do need your therapeutic support system, that's very important, right. But thinking of other, uh, autistic led, positive social media groups, so on Facebook reframing autism is great.

# Maisie Soetantyo (26:15):

There are, uh, a few of really, really good ones. But I think in general, if you're a parent, if you're your clinician come into this social media group, whether it's Facebook or Instagram or Quora and ask your questions, you know, and if you feel like, Oh, I learned a lot from this group, then stay. If you're being trolled, or if people trying to focus on your language, like, Oh, don't say it like this leave. That's what I do. You know, I just leave because I want to learn. I want to learn from other autistic adults who are

ahead of me. I want to learn from other autistic clinicians, you know, so whenever I don't have good feeling, I just why stay? That's what I say to parents. Right.

## Kelly Bron Johnson (27:00):

Uh, so you also started a non-profit, uh, autism career pathways, um, with a mission to increase the hiring and longterm retention rates for autistics in small and medium size companies. Why did you, uh, decide to focus specifically on small and medium companies?

## Maisie Soetantyo (27:19):

Because small and medium size companies are actually workplaces that autistic people can really thrive better because it's smaller, quieter, slower, and the jobs are often very systematic, or you can actually do one assignment at a time, learn it well, and then move on. Um, you know, there are always pros and cons here in the Bay area, San Francisco Bay area, we have mainly pioneers, right? We have SAP, Google. We have all these, uh, tech companies who are based here and they really, for years have really tried to figure out how to hire autistic people. But they're looking for a specific skillset usually, which is the technical like app tech skills aptitudes. And I would really want to represent, uh, autistic adults who have different types of aptitudes and talents and interests. I'm talking about the autistic makers, uh, autistic, uh, business owner, home-based businesses, people who want to do freelancers.

### Maisie Soetantyo (28:34):

For example, there's so many great ideas that I have learned since 2019 about just a little, not little, just, just community opportunities for autistic people. So for example, there is a non-profit in Chicago where they have set it up with their downtown business. So every weekend a van would come out with whoever's working, autistic adults working. And what they do is they pick up like documents that need to be shredded. Uh, you know, and then they pick up from all the businesses like every weekend and it's a subscription model. So every weekend our guys hang out, they socialize and they do this. Paper shredding. Now you think about your shop, like your, your businesses in our community, how many real estate offices, law offices, uh, you know, all these businesses who have papers, stacks and stacks of papers that needs to be scanned, documented, filed, and shredded, you know, like that that's one idea.

#### Maisie Soetantyo (29:48):

Yeah. So there are so many amazing ideas that people who want to really somehow make a difference in Neurodivergent employability. And they're able to think outside of the box and actually make it happen, you know, and that's what autism career pathways. We want to shine a spotlight on that so that we can perhaps do the same at our downtown business, you know, because I think people don't know what they don't know. And if people don't know the how to, they're not going to open the doors, you know, I've experienced that knocking on a door only to be told, well, you know, what we do here is to specialize, too fast pace. You know, that's what they say.

## Maisie Soetantyo (30:35):

And I stopped doing that. I realized I have to show them how to, and how we want to do that is to build an online platform where we house a very robust video training resources to show all at the click of a button. This is how you employ, how you screen and important do onboarding and employment, support autistic people at the library, right? Uh, all at the click of a button, short video clips, I also have created the capable tool, which is a career, all skill base career assessment tool it's called capable. And it's designed to really showcase, uh, the personality of the person, what they're interested in, what

they're really good at, and it shows the work sample. So what comes out of that is actually a video resume is short, edited, caption five to seven minute video resume, uh, with a very simple color coded video summary that the job seeker can take, okay, this is me. And then this is the picture visualize, Oh, this is a really good person, you know, good energy and have the skillset within their company, whatever that it may be. You know? So I, that's what I'm trying to do. My dream is of course you have capable replace a standard for interview that is still commonly use.

## Kelly Bron Johnson (32:00):

I kind of, I agree with you there in the sense of like working on small and medium sized businesses, you know, I have a consultancy as well, but I started with like, I'm going to work with whatever big businesses and see what I can do. And I've come to see that, you know, a lot of the resistance and it's hard to be a cog in a machine, you know, with these big companies. Whereas what I'm starting to see is it's individuals. So individual entrepreneurs or small businesses who have somebody that they know, usually somebody in the family they know has some sort of disability or something. So they understand the importance of it already. And they want to make personal change in their own lives or their own business. And I find that is, uh, A lot of the change is coming from, and yeah, easier. It's Easier if I already have, I already broken down one barrier

Kelly Bron Johnson (32:47):

When they go, yeah, we know this person has value. Let's bring more in, you know, exactly.

## Maisie Soetantyo (32:52):

Like, I don't understand why libraries across America are not looking for autistic interns, autistic librarian. I know a few of people working successfully, you know, the library I'm about to interview Erin, who is, she is an NBA number analysts. Um, I'm a sport. Um, my obsession on the side is sports and basketball in particular, and Erin works for Memphis Grizzlies. So I'm going to interview her and that, to me, that's a dream job. And yeah, so there are these like opportunities. And I admire like, uh, organizations like the Memphis Grizzlies who has taken the initiative to hire somebody and fully allow the person to disclose. That's the other thing self-disclosure process that's really hard. Right. And, uh, imagine if the Lakers are doing this, you know, imagine if this process, if I can show the process, the onboarding process to the Lakers or the golden golden state warriors here, you know, just one person, you know? Um, and it will just continue to have that dominoe, positive domino effect. That would be amazing.

Doug Blecher (<u>34:17</u>):

Well, Maisie, I have a special interest of basketball as well. So that could be, yeah, that could be a totally different conversation. Yeah. I know a seven hour podcast and that won't be good. So we will,

Maisie Soetantyo (34:35):

We can start with this, Doug. We can start with like, which athlete do you think is a neurodivergent? Because I have a few that I think

Doug Blecher (<u>34:45</u>):

There's too many too, to just pick one. I would, I would say

Maisie Soetantyo (34:50):

I, now I know, but that will be really fun conversation.

Doug Blecher (<u>34:55</u>):

Yes. Yes. I think there's, I think there's many athletes out there and they just you know, they don't realize they're neuro divergent or they have, or they're just not comfortable disclosing in that environment and culture.

Maisie Soetantyo (35:09):

Right. Well, people don't know what they don't know. Right.

Doug Blecher (<u>35:14</u>):

Well, before we let you go, um, we always like to learn from our guests, you know, because me and Kelly started this podcast, um, because we weren't seeing enough stories about the intersectional identities of autistic folks. So for you, like moving forward, what types of stories would you like to see highlighted?

Maisie Soetantyo (35:39):

I think everyone has a story and only that person can write his or her or their own story. And I wish to see more stories from the other side of like neuro-typical people to really share, to be part of non-dairy origin story. You know? So then my that's my wish to be able to see more books children's books from the neuro-typical community to say, this is how I equip myself so that I can, so I can guide somebody like this because it's a win-win situation, you know, to, to have a connection, to be able to mentor a person who is different in appearance in the way they connect with you. And, uh, I think it's, it's really a privilege to be part of that versus the story, not the other way around, honestly, this is what I, this is my dream. My husband sometimes say, it's just in your mind, nobody would buy that. My husband is, uh, brings me back down to earth because I'm a dreamer. And I refuse to settle.

Doug Blecher (<u>37:05</u>):

Settling is way overrated. Well, Maisie, thanks so much for, uh, the conversation today and making time to talk with me and Kelly.

Maisie Soetantyo (37:17):

Yeah. Anytime, anytime. Thank you so much.