

Social communication and developmental disorders with Connie Kasari

In this episode of “Synaptic,” Kasari talks about the need for inclusion in educating autistic children, what drew her into the autism research field, and growing up on the family farm.

1 June 2023 | by BRADY HUGGETT

This transcript has been lightly edited for clarity; it may contain errors due to the transcription process.

[opening theme music]

Brady Huggett

All right. This is “[Synaptic](#),” episode two of “Synaptic,” our podcast that explores the people, the science and the challenges of autism research, and to some extent, the greater neuroscience space. I’m the host of the show, and my name is Brady Huggett.

[transition music]

Brady Huggett

All right, let’s get on with this episode. And we’re going to start in the northeastern part of Oregon. There’s a little town there called Echo. The Columbia River, which is the demarcation between Oregon and Washington state, is about 15 miles due north of Echo. Uh, the town has a little historical significance. The Oregon Trail ran just south of it, for instance, but otherwise, there is not a lot to Echo, to be honest.

Its official area is just 0.6 square miles, and its population in the 2020 census was only 633 people, but a few generations ago, a man from Finland got off a boat in the United States and made his way west and started a farm in Echo. And that farm was where Connie Kasari grew up. That’s our guest for today, Connie Kasari. When she was growing up in Echo, the population was less than 500 people, and she still goes back there to visit at least once a year. We talked about that on this podcast.

We also talked about the fact that her mother’s father was a farmer, and we talked a little about Oregon and how she values the, as she said, “rugged and independent people there.” We talked about using the JASPER treatment approach with autistic children. We talked about the problems with ABA [applied behavior analysis], and we even talked about the International Society for Autism Research conference, colloquially known as INSAR, as Connie’s the past president of that society. Of course, we talked about why she chose the career she did.

All that is coming up in this hour now. I recorded Connie at her office in the Semel Institute for Neuroscience and Human Behavior on the campus of UCLA. I set up two mics over her desk, and afterwards she walked me through parts of her lab and I got to meet a few of her grad students. But let’s pick the talk up here where Connie and I are looking at some art that hangs on her office wall. This art was created by an autistic young man she has known since kindergarten named Leland. So this is episode two of “Synaptic” with Connie Kasari starting right now.

[transition music]

Connie Kasari

So I scan the art.

Brady Huggett

Now, does that look amazing?

Connie Kasari

Usually it just —

Brady Huggett

Oh, I see — I see what you mean.

Connie Kasari

Oh, there's Leland.

Brady Huggett

Maybe it was supposed to come up.

Connie Kasari

Usually —

Brady Huggett

But it has like a 3D element almost too. Yeah.

Connie Kasari

It has sound and stuff, you know. So he's — no, he's talented. Um, but he didn't do well in inclusion because nobody, you know, they have such low expectations.

Brady Huggett

Yeah.

Connie Kasari

So that's still the battle I fight today.

Brady Huggett

All right, well, let's get it — we're rolling by the way.

Connie Kasari

Yeah, we're rolling. Oh, OK. OK. Oh my goodness.

Brady Huggett

Um, well, the first — so you mentioned what I was gonna open with, which is you've been on this campus for over 25 years, now you're telling me over 30 years.

Connie Kasari

Over 30 years. Yeah. I came in 1985.

Brady Huggett

Well, I mean, is that because you have found UCLA to be the best place for you, or that you're done with your travels or what, you know?

Connie Kasari

Um, well, I finished my Ph.D., got married, and then we traveled out here, um, both for postdocs in this NIH.

Brady Huggett

Uh-huh.

Connie Kasari

Um, and I'm from Oregon.

Brady Huggett

Oh, that was the thing.

Connie Kasari

So for me, coming, that was the thing, back west was really great.

Brady Huggett

OK. So that, let's go there. So where, where were you actually born? And I know you went to Oregon for college, and we'll get there, but were you born in that area?

Connie Kasari

Uh-huh. I was born in eastern Oregon near Pendleton.

Brady Huggett

Uh-huh.

Connie Kasari

So I grew up on a farm, then went off to college and was —

Brady Huggett

Like a generational farm. Your family were farmers?

Connie Kasari

My father was a farmer, yes. Mm-hmm. Right in eastern Oregon.

Brady Huggett

So —

Connie Kasari

I was first to go to college and my, my — all of the — my parents had four kids. We all went to college, so, but we — but they didn't go to college.

Brady Huggett

Yeah.

Connie Kasari

So we were first generation.

Brady Huggett

But was that a generational farm, or —

Connie Kasari

No, I mean, let's see. I guess my father's father had also farmed. Yeah. My father's father was from Finland.

Brady Huggett

Uh-huh.

Connie Kasari

Settled in eastern Oregon, was a farmer. And my father was a farmer. Um, but he also had a busi — a farm business.

Brady Huggett

Like, um-

Connie Kasari

Fertilizers.

Brady Huggett

So selling fertilizer?

Connie Kasari

Yeah.

Brady Huggett

Perfect. OK.

Connie Kasari

Yeah. After he, he was a farmer. And then, uh, we sold the farm and he moved to a fertilizer business.

Brady Huggett

Oh, I see. OK.

Connie Kasari

But we still lived on a farm.

Brady Huggett

But his father came over from Finland and —

Connie Kasari

And was a farmer —

Brady Huggett

To, to the U.S. and started a farm. So somehow he came over, matriculated across the country, and started a farm in Oregon. Wow. That's amazing. Yeah. And then what about your mother's side of the family?

Connie Kasari

Um, she also, uh, her father, I believe also was a farmer, grew up in Idaho and Oregon. That area.

Brady Huggett

Met your dad and moved.

Connie Kasari

Uh-huh. Um, met my father in Oregon, I believe. I mean, she was 18 or 19 when she got married.

Brady Huggett

What was she doing in Oregon? How'd she get from Idaho to Oregon at that age?

Connie Kasari

Actually, I think she was born in Oregon. And then my grandparents later moved to Idaho, so I'm not sure she ever really lived in Idaho.

Brady Huggett

Oh, I see. So she met him in Oregon.

Connie Kasari

Yeah. She met him in Oregon. Yeah, there — we were Oregonians. There were a lot of Finns though that settled in Oregon, especially around the Portland area, Finn Hill, and that, that area.

Brady Huggett

So you're half Finnish?

Connie Kasari

I'm half Finnish, yep. Mm-hmm.

Brady Huggett

Do you ever go to Finland?

Connie Kasari

I've been there a couple of times, yeah.

Brady Huggett

Do you — like, did your father go back and you looked up family, that whole thing?

Connie Kasari

Uh, we did. My — I took my father back for, you know, the first time probably 32 years ago. And so he did look up relatives.

Brady Huggett

Oh. So he had never been.

Connie Kasari

He had never been.

Brady Huggett

Oh, amazing.

Connie Kasari

Mm-hmm. Right.

Brady Huggett

Wow. OK. So you're growing up on this farm.

Connie Kasari

Mm-hmm.

Brady Huggett

Your family is not, I'm gonna say academically inclined, or you did not come from professors, your parents were not.

Connie Kasari

Right.

Brady Huggett

So how did you — how many siblings do you have? You have three.

Connie Kasari

I have three sibs. Uh-huh.

Brady Huggett

Boys, girls.

Connie Kasari

Uh, there were two boys and two girls.

Brady Huggett

Mm-hmm. So how did you all end up going to college? Was it like —

Connie Kasari

It was valued?

Brady Huggett

Yeah.

Connie Kasari

So my parents really valued education. My mother always tells this story that she got a scholarship to be a nur — to go to nursing school to be a nurse. And my and her father told her that if she went away to college, that she could never come home again because they grew up in the Depression.

Brady Huggett

Uh-huh.

Connie Kasari

And there she was one of seven siblings, or seven kids. And so the idea there was that you didn't go to college, you just worked and you helped the family and those kind of things. So instead she got married.

Brady Huggett

Right. So in her father's mind, if you left the family to go to nursing school, then you've sort of broken this tie to the family and don't come back —

Connie Kasari

Yeah.

Brady Huggett

'cause you have not helped us in this moment. Uh-huh.

Brady Huggett

Right. Yeah. Why would you be privileged to be able to do that? Yeah, so they, both my parents really valued education even though their, um, parents did not go to college. In fact, my grandfather who came from Finland, had only gone to three days of school.

Brady Huggett

In his life.

Connie Kasari

In his life.

Brady Huggett

In Finland.

Connie Kasari

Mm-hmm. But he was a very talented musician and —

Brady Huggett

What did he play? The, um —

Connie Kasari

He played the violin, and he played, or he called it the fiddle and, um, the accordion.

Brady Huggett

So he — you're telling me he had three days of school in Finland someplace?

Connie Kasari

Mm-hmm.

Brady Huggett

Did he come by himself to the U.S.?

Connie Kasari

Yes.

Brady Huggett

Totally by himself. As like a young man in his 20s or something like that.

Connie Kasari

Yep.

Brady Huggett

Came all the way where he started a farm that gets handed down to your father. Your father meets your mother. Your mother squelches her dreams of being a nurse, marries your father, starts a family.

Connie Kasari

Mm-hmm. Yeah. Had four kids in five and a half years.

Brady Huggett

Oh my God. The first one at 18.

Connie Kasari

Probably 19. Yeah.

Brady Huggett

Yeah. Wow. And they're still together?

Connie Kasari

Uh, well, my father's died. Yes. But they were, yeah, still together. Well, he died at 95 and she's 92 and very healthy. Uh-huh.

Brady Huggett

Have you had your genome sequenced?

Connie Kasari

[laughs] Um, he did that, you know, uh —

Brady Huggett

23andMe.

Connie Kasari

Whatever it's called. Yeah. One of those. I don't know which one.

Brady Huggett

23andMe.

Connie Kasari

Yeah. One of them he did. And because we always thought that maybe he was really Estonian because in Estonia that you see the last — my last name, Kasari —

Brady Huggett

Uh-huh.

Connie Kasari

— lakes and towns and various places. So it's more Eastern European. Um, turned out he was 99 percent Finnish.

Brady Huggett

What was that 1 percent?

Connie Kasari

I don't know. Some —

Brady Huggett

Something else.

Connie Kasari

Yeah. Something else.

Brady Huggett

OK. So I wanna know about, like, you're growing up and you're saying your parents are saying, "Look, uh, you need to go to college. It's an opportunity that when you take advantage of. There's a good public school, in fact, a state school right around the corner."

Connie Kasari

Yeah. Um, Well, it was four hours away, but yeah. Well, no, I think that we just never thought we wouldn't go to college. We always grew up, all of us knowing that we would go to college. And I just followed my, you know, brother and sister to Oregon State. I didn't even think about it.

Brady Huggett

Uh-huh.

Connie Kasari

I didn't have a choice. I just followed them there. My brother was just a year and a half older than me, a year ahead of me in school. Um, and he was a veterinarian.

Brady Huggett

Uh-huh.

Connie Kasari

And, um, so kind of related to farming.

Brady Huggett

Right.

Connie Kasari

And my sister ended up becoming a teacher, but my younger brother did a-agriculture economics, so farming, and my sister lives on a farm.

Brady Huggett

Oh, she does?

Connie Kasari

Mm-hmm. In Texas.

Brady Huggett

A working farm?

Connie Kasari

Um, well, they are both teachers, but yes, they have, uh, cattle and, you know.

Brady Huggett

Yeah. It's not their main source of livelihood, but it's a working farm.

Connie Kasari

No, no.

Brady Huggett

Yeah.

Connie Kasari

I mean, I think, uh, my — all of my family is kind of oriented towards farming.

Brady Huggett

Do you have those sorts of memories of the farm and —

Connie Kasari

Mm-hmm.

Brady Huggett

— things that you — do you, do you wish that you lived on a farm, you know, that kind of thing, versus the middle of Los Angeles?

Connie Kasari

[laughs] I certainly never wished that [laughs] growing up. I always wanted to go away and not live there because it was a very small.

Brady Huggett

Yeah.

Connie Kasari

You know, very small school, not a lot of opportunities there. And so for me, it was always, I would — you know, go away. But I — there's, it's very peaceful to be on farms.

Brady Huggett

Yeah.

Connie Kasari

So I enjoy those kind of vacations. Um, and I guess I wouldn't rule that out at some point, but I don't think about it —

Brady Huggett

No.

Connie Kasari

— in the same way,

Brady Huggett

Do you miss the Pacific Northwest?

Connie Kasari

Oh yeah. I think the Pacific Northwest is great, but I think California's great too.

Brady Huggett

Well, for obvious reasons, right?

Connie Kasari

Yeah.

Brady Huggett

I mean, it's sunny and 75 every day. Well, it feels like it to me.

Connie Kasari

That's right.

Brady Huggett

Um, yeah. 'Cause the Pacific Northwest has a really unique, it's almost like, um, a temperate rainforest in that way.

Connie Kasari

Yeah. But the people are kind of rugged and independent and —

Brady Huggett

Yeah, absolutely.

Connie Kasari

— all of those things I value.

Brady Huggett

Yeah. Good. OK. So anyway, you're, you're going to school and how did you — did you think — what, what did you think you were gonna do in college?

Connie Kasari

Well, I thought I would do special education, which is what I ended up eventually doing.

Brady Huggett

How come?

Connie Kasari

Um, I think as a kid, growing up in these small rural schools, if there was ever a kid with a disability, they just went to school with you. And so I remember sort of taking, uh, I remembered sixth grade taking this young boy with emotional problems sort of under my wing and just being kind of interested in him. And then in high school, you know, small school didn't have much to do.

I kind of, uh, I would go and help the teachers in the younger grades with kids, and I was always attracted to the kids who had learning problems or had a difficult time. So I was motivated by that. So when I got to Oregon State, I don't know what I wanted to do. I just went into psychology and education and was really motivated, motivated still, by learning differences.

Brady Huggett

Hmm.

Connie Kasari

So then I went from Oregon State to Peabody College and —

Brady Huggett

And Vanderbilt.

Connie Kasari

Yeah. In Nashville. Right. My brother, my older brother drove across the country with me and dropped me off. Yep.

Brady Huggett

How'd that feel? That's a big change.

Connie Kasari

Uh, it was a big change. Yep. It was a big change. It was interesting. I liked it. I was always up for adventure.

Brady Huggett

Yeah.

Connie Kasari

So that was fine. Did my master's and got really interested again in disability, and then moved to Richmond, just kept going east to Richmond, Virginia. Um, I actually taught at Fredericksburg, Virginia, for a couple of years.

Brady Huggett

I did not know that. OK. So when you, when you went to get the master's, you thought even when you left Oregon, um, you're thinking, "OK, I'm gonna be a teacher, I'm gonna be a special ed teacher."

Connie Kasari

Yeah, that's right.

Brady Huggett

And so the master's degree was really just sort of — I mean, you could have done that without the master's degree, I'm assuming?

Connie Kasari

Uh, no, because it wasn't special ed at Oregon State, so I had to get a master's in, sort of, learning differences.

Brady Huggett

OK.

Connie Kasari

And at Peabody, I really learned a lot about assessment and kids with disabilities. And you could kind of do one or two tracks. You could kind of go down a research track or you could just do a clinical, and I sort of, um, I think I did the research track, actually. Um, although it felt pretty clinical as well. And then I just went into teaching for four years, two in Fredericksburg.

Brady Huggett

Mm-hmm.

Connie Kasari

So it was, it was the period of time in which I went to college was where it was like the late '70s, early '80s. And so kids with disabilities were just coming into public schools, believe it or not.

Brady Huggett

Oh, you mean like out of the institution almost. The first time they were certainly brought in.

Connie Kasari

Well, they're — are home.

Brady Huggett

Yeah, yeah.

Connie Kasari

They were at home. Right.

Brady Huggett

Yeah.

Connie Kasari

They weren't allowed to go to school.

Brady Huggett

Yeah.

Connie Kasari

So we were doing a lot of child find at that time of kids with severe and profound disabilities in trying to bring them into school. So that was one of my first experiences was actually in Tennessee in the summer, bringing in these kids from the rural parts of Tennessee into schools. I mean, these were kids that were in bed all day. They were severe and profound.

Brady Huggett

Yeah.

Connie Kasari

I don't know what we were thinking.

Brady Huggett

Yeah. How did you — I mean, that's the, the thing, like today we would have a better idea on how to handle that, but back then it must have been, you know, you're breaking new ground on a daily basis.

Connie Kasari

Yeah. Absolutely. So —

Brady Huggett

Sounds incredibly hard.

Connie Kasari

Yeah. [laughs], these kids were coming to school and some of them we really needed to be in home with them because they were older and they weren't that medically stable.

Brady Huggett

Yeah.

Connie Kasari

Um, and so then when I went to Richmond after that summer, I got a job and lived in Richmond, but I had a job in Fredericksburg and they were all, what they called back then, severe and profound. So I had 17 kids in a classroom with another teacher and two aides, and the kids were mostly not mobile.

Brady Huggett

Yeah.

Connie Kasari

Um, but they ranged from about 3 to 21 in the same class, which was crazy.

Brady Huggett

Right. How can you study curriculum with that range?

Connie Kasari

Well, I — we did, we did a — had a lot of rare syndromes. I did a lot of reading on what to do, and we did a very developmental approach with them because they didn't — there weren't like pre-made curriculums, you know, were just —

Brady Huggett

Yeah. No, that's what I mean.

Connie Kasari

Yeah.

Brady Huggett

So you're just sort of doing it daily on your — you're figuring it out day by day, almost.

Connie Kasari

Yep.

Brady Huggett

Wow.

Connie Kasari

Yep.

Brady Huggett

Wow.

Connie Kasari

But we did a lot of interesting things. So I worked two years there, and then I — then I took a position at, uh, VCU, Virginia Commonwealth University.

Brady Huggett

Yeah.

Connie Kasari

And we were working with babies because that was also a new area. So birth to 2, and these little babies that were very low resourced, put them on a bus two days a week, they would go to a public school and then two days a week in-home, um, sessions.

Brady Huggett

Basic language skills, I think.

Connie Kasari

Basic — yeah. Develop — basic developmental skills.

Brady Huggett

Yeah, yeah.

Connie Kasari

Attending, um, most of them — well, we worked a lot on motor skills because they weren't ambulatory.

Brady Huggett

Right.

Connie Kasari

So —

Brady Huggett

But I'm, so — I'm so at this point, you know, you've got a wide range — You've gone from well older all the way down to zero and 2. You've seen children —

Connie Kasari

Mm-hmm.

Brady Huggett

— all the way from zero to about 25. I don't know, something like that.

Connie Kasari

Right. But their developmental skills were not that broad.

Brady Huggett

Uh-huh.

Connie Kasari

So they were all pretty severe and profound. So we're talking about what are those developmental skills of kids between birth and age 5. So that's what we focused on, and I focused a lot on sort of movement and positioning.

Brady Huggett

Mm.

Connie Kasari

Because the kids were really severe and profound.

Brady Huggett

Yeah.

Connie Kasari

I mean, these were like — this was a new area. Um, so it was- it was kind of exciting. I learned a lot. Um, but I only worked four years, and then I went to do a Ph.D. 'cause [crosstalk]

Brady Huggett

Listen, when, when teachers talk, when they talk about teaching, it's exhausting.

Connie Kasari

Mm-hmm.

Brady Huggett

And it's hard to keep kids in line, and they come home at the end of the day and they're exhausted. I'm, I'm assuming that's probably the same with the work you were doing.

Connie Kasari

Yeah. I mean, I was pretty interested in the work, but it wasn't like a long-term commitment for me because it doesn't go any — teaching — It's hard with teaching, you know, you don't have, um, the advancements that you really need.

Brady Huggett

You don't see like the kind of growth you're saying.

Connie Kasari

Yeah. Like, what was I gonna do? Nobody — we were in the basement often of public schools. I was in regular public schools, and we were always working and trying to make, you know, sort of gains and awareness and inclusion and acceptance and, but yeah. You can only fight that battle for so long on such a small level. So you wanna go and, and do on a larger level. So that's —

Brady Huggett

So that's why you did the Ph.D., right?

Connie Kasari

Mm-hmm, yep.

Brady Huggett

So you're sort of under-resourced, stuck in the basement often, and —

Connie Kasari

Yeah.

Brady Huggett

We're not getting any — you're not making any real progress here. OK. That makes sense.

Connie Kasari

I mean, special ed was always in the basement. Special ed was always kind of marginalized.

Brady Huggett

Yeah.

Connie Kasari

It continues to be marginalized.

Brady Huggett

Yeah.

Connie Kasari

That hasn't shifted that much in 30-some years.

Brady Huggett

Yeah.

Connie Kasari

Um, yeah. I mean, our, our terminology has shifted and changed, but our need for interventions is still as strong as it's ever been. So now we argue for kids to be in inclusion and to have their needs met. So it's not OK to just put somebody in a classroom and say, "Well, you can come and you can sit." You know, that's not educating them. And so we do wanna educate them within the context —

Brady Huggett

Yeah.

Connie Kasari

— of whichever classroom they're in.

Brady Huggett

Yeah, you, so are you saying sort of like the old version of inclusion was, yes, you can come into the room and sit with us, but there was real no, no specific instruction, and that's the change.

Connie Kasari

And that still happens today.

Brady Huggett

That still does.

Connie Kasari

Oh, yes.

Brady Huggett

Yeah.

Connie Kasari

Mm-hmm.

Brady Huggett

Yeah.

Connie Kasari

If they're lucky enough to get into the inclusive classroom.

Brady Huggett

Yeah.

Connie Kasari

People are still putting up barriers, roadblocks to having kids in their classrooms.

Brady Huggett

I'm assuming this is coming from the parents.

Connie Kasari

No, well, sometimes it comes from parents, but it comes from teachers too.

Brady Huggett

Uh-huh.

Connie Kasari

So the teachers union will restrict the number of kids on an IEP that can be in a classroom.

Brady Huggett

Because they feel it's gonna be disruptive or something?

Connie Kasari

Disruptive, too much work, and so on and so forth. So, you know, we need to have new models for this to actually happen successfully. And there are models out there. We know what to do —

Brady Huggett

Hmm.

Connie Kasari

— and we know how to do it, but we don't do it.

Brady Huggett

Why?

Connie Kasari

That's a good question. I think it starts at the top. I think that our schools of education, our training of teachers has to be better, more responsive, more responsible, but we still are not there.

Brady Huggett

Yep.

Connie Kasari

So I, you know, for 30-some years I've been trying to work on this.

Brady Huggett

All right. So you go to, you go to Chapel Hill.

Connie Kasari

Mm-hmm.

Brady Huggett

For your Ph.D. And what was your dissertation? I, I don't know actually.

Connie Kasari

Oh, my dissertation, [chuckles] was on infants, 6- and 10-month-old infants with disabilities. They were pretty severe disabilities. And looking at, uh, parent-child interactions and the kinds of cues that parents would pick up on to, um, determine if their kids were communicating with them. So —

Brady Huggett

And you sort of, you —

Connie Kasari

— I'm still doing the same work —

Brady Huggett

Yeah.

Connie Kasari

— in a sense. [chuckles]

Brady Huggett

But that was, that was sort of quantifying.

Connie Kasari

Mm-hmm.

Brady Huggett

You would observe and say, "These are the things that parents are picking up on."

Connie Kasari

Yeah. Readability of those infant signals.

Brady Huggett

And that can then be compiled into, well, here's what we think symptoms of autism are.

Connie Kasari

Well, it wasn't autism back then. It was, these were just disabled babies. Babies with, um —

Brady Huggett

Learning disabilities, yeah.

Connie Kasari

Different — yeah. Down syndrome or other — it was a mixed group of kids and typical kids.

Brady Huggett

Both.

Connie Kasari

Mm-hmm.

Brady Huggett

OK. So you almost had like a control group there.

Connie Kasari

Mm-hmm.

Brady Huggett

Right. All right. So you finish, um, that was in 1985, I think you graduated from.

Connie Kasari

Yeah, a long time ago.

Brady Huggett

OK, yeah. [laughter] Did you — when did you meet your husband if you both came west together?

Connie Kasari

Um, uh, when I was in my Ph.D.

Brady Huggett

You did?

Connie Kasari

Yeah.

Brady Huggett

OK. You both finished around the same time?

Connie Kasari

Mm-hmm.

Brady Huggett

And then did you both come to UCLA?

Connie Kasari

Yeah. Mm-hmm.

Brady Huggett

By chance or by planning?

Connie Kasari

By planning.

Brady Huggett

Yeah. OK.

Connie Kasari

Mm-hmm.

Brady Huggett

So tell me that you came on an NIH grant, right, a fellowship.

Connie Kasari

Yeah. We were both on the same NIH grant. Mm-hmm.

Brady Huggett

OK.

Connie Kasari

T32. Right. I worked with Marian Sigman.

Brady Huggett

So, so tell me, you came — this is '85, you came out here, you obviously didn't — you just were on the fellowship. I don't know, I think by — so five years you were on the fellowship?

Connie Kasari

Three years and then three years on the fellowship, and then two years as a staff psychologist here in Semel. And then, um, this job opened in the School of Ed, and so I applied, and you know, that's where I've been ever since.

Brady Huggett

The rest is history.

Connie Kasari

Yeah, right.

Brady Huggett

Right.

Connie Kasari

As they say.

Brady Huggett

OK. So tell me about moving out here and what that was like. So, I mean, as you said, West Coast was nice for you. I mean, it's not Oregon, but —

Connie Kasari

Yeah. Yeah.

Brady Huggett

— you didn't think, obviously, that you were gonna be here the next 30 years. I don't imagine you would've thought that.

Connie Kasari

No, I wasn't sure I wanted to do academics, period. Um, yeah, that was a shift. I mean, I think that the postdoc with Marian was really good for that in that the kind of work we were doing, the fact that I started to work on autism. I wasn't working on autism until I get my postdoc.

Brady Huggett

Oh, that's where you were introduced it, yeah.

Connie Kasari

Mm-hmm.

Brady Huggett

Yeah.

Connie Kasari

And I think it's a really fascinating area to study in. And then UCLA has all of these interesting studies going on, interesting people, and so I really got hooked. Um, and then I was always interested in education. So this job in education was a perfect kind of, uh, transition for me. And also, Marian was telling me I needed to do something on interventions, which I also hadn't done. We were just doing descriptive studies.

Brady Huggett

Why, why was she saying that?

Connie Kasari

Because we knew so much about the kids and the kinds of skills that were missing in their development, and so why not try to intervene on those?

Brady Huggett

So she was saying, you've gathered this information, let's try to apply it in a way.

Connie Kasari

Yep, yeah.

Brady Huggett

OK.

Connie Kasari

So she really encouraged me to do the intervention studies.

Brady Huggett

When you came across autism —

Connie Kasari

Mm-hmm.

Brady Huggett

— I mean, and I understand that this was — the definition was a lot different than it is today, but what, what was fascinating about it?

Connie Kasari

Oh, just that, I mean, I used to say that working with Down syndrome kids, you would work with them and you would be, you know, if you're sitting at a table, you're like everything to that child, you're like the only thing in the room. And yet when you sit down with a child with autism, you weren't even in the room. So the feel of just the interaction was so

different and fascinating. So, you know, trying to figure that out and trying to help kids have a happy life, a productive life. And so that to have a productive happy life, you need to be able to talk or communicate in some way.

Brady Huggett

Yeah.

Connie Kasari

So I really focused in on that social communication piece because that is the — you know, regardless of whether you have intellectual disability or not, you still need to be able to communicate in some way.

Brady Huggett

So that was the fascinating part.

Connie Kasari

Mm-hmm.

Brady Huggett

So, but also I think it sounds like you're saying it was a change. You're used to this kind of person in front of you, and suddenly you had almost an, an opposite one —

Connie Kasari

Opposite experience.

Brady Huggett

— and though, this is a different thing, yeah.

Connie Kasari

Mm-hmm.

Brady Huggett

OK, so let's try to figure this out.

Connie Kasari

And both of them need to learn to communicate, but with the kids with Down syndrome or other kinds of developmental disabilities, you know, progress is just slower, but it feels like you're connected and making those changes together. Whereas with kids with autism, it just felt substantially different.

Brady Huggett

Yeah.

Connie Kasari

And yet at the same time, what I learned by, you know, working with Marian and doing this work for a number of years is just the heterogeneity. So it's all over, all over the map. And so that also is really interesting how you could be a savant, you know, a brilliant, or like Leland —

Brady Huggett

Yeah, yeah.

Connie Kasari

— who does this art —

Brady Huggett

Yeah.

Connie Kasari

— in my office. He's obviously an amazing artist and brilliant in his own way, but he's minimally verbal. To me that's fascinating.

Brady Huggett

Yeah.

Connie Kasari

And then I have people that work in my lab that are highly verbal and also very talented, but a very different kind of person.

Brady Huggett

Yeah, so that was part of the fascination.

Connie Kasari

Yeah.

Brady Huggett

Yeah, but what was the concept of autism at the time? If you're — can you remember the sort of, like, what a classic definition would've been?

Connie Kasari

Well, with working with little kids that most of them didn't talk, 75 percent of them were not talking when they entered school —

Brady Huggett

Yeah.

Connie Kasari

— at age 5. That has drastically shifted. Now it's about 30 percent.

Brady Huggett

Hmm.

Connie Kasari

So we've done something well.

Brady Huggett

Yeah.

Connie Kasari

You know, inter-, early interventions have made a huge difference. So that would've been classic. Um, just the fact that they might not have wanted to interact with you, the relationships were sort of more fragmented. Um, I — to me, those were the things. I, I didn't see the behavioral issues as much. I mean, some people talk about a lot of behavioral challenges and there can be, but I don't think of that as core.

Brady Huggett

Right. Uh, well, tell me where I'm wrong, but sometimes that is tied to the inability to communicate.

Connie Kasari

Yeah, absolutely.

Brady Huggett

Yeah, yeah. OK, so I think in — I think you set your lab up in 1997.

Connie Kasari

Mm-hmm.

Brady Huggett

Your first time. Is that right?

Connie Kasari

Possibly. That's when I started having grants here.

Brady Huggett

Uh-huh.

Connie Kasari

Um, through Semel, I had moved from Semel as a postdoc to, um, School of Education. So for those first few years, I was mostly doing work on Down syndrome.

Brady Huggett

Mm.

Connie Kasari

So I was kind of creating my own independent line of research away from Marian. And then Marian got the CPEA, which is the Consortium of Programs of Excellence in Autism, those first set of grants, um, in 1997, and I had a project in that. That was my first intervention study.

Brady Huggett

I see. OK.

Connie Kasari

So that's when we probably set up a lab here in that we were seeing kids that were in this, um, early intervention program here.

Brady Huggett

So when you set your lab up, how did you — I mean, how did you do it? How did you find the-, these postdocs to work with you? How did you build a reputation so that people wanted to come here and learn? I mean, how did you do that whole thing?

Connie Kasari

Well, I remember I was in the School of Ed. I already had about 30 Ph.D. students.

Brady Huggett

Yeah.

Connie Kasari

When I was an assistant professor, the — all the other professors retired or moved in my division. I was the only one left, and there were like 35 Ph.D. students [laughs].

Brady Huggett

So you inherited them, is what would tell me?

Connie Kasari

I inherited them all. So I didn't have any problem attracting students. I was just trying to weed through them to, you know, help them finish up.

Brady Huggett

Yeah.

Connie Kasari

Um, so I had — yes, I had graduate students already, and then I had a lab here, and we started to see kids off of the early intervention program that's upstairs, uh, one floor up.

Brady Huggett

Uh-huh.

Connie Kasari

And so I did this randomized, controlled trial where we just randomized the kids who came into that program to different intervention components and tested those.

Brady Huggett

OK. So this — um, I was looking at your papers, and I think this — tell me if I'm wrong with, I think your first paper is still maybe your most cited, or that might be a function of time, right? Is this —

Connie Kasari

I have no idea.

Brady Huggett

— a longitudinal study of joint attention and —

Connie Kasari

— play.

Brady Huggett

Oh, no. Language development in autistic children. Is that right?

Connie Kasari

Could be.

Brady Huggett

Yeah.

Connie Kasari

Yeah.

Brady Huggett

So can, can you tell me about that paper? Like what were you trying to get at when you started looking —

Connie Kasari

Was this —

Brady Huggett

— and then what did you find?

Connie Kasari

Was this the intervention paper?

Brady Huggett

I think so.

Connie Kasari

So I don't know which ones were cited, and I don't pay attention. Um —

Brady Huggett

This was a, I think, uh, —

Connie Kasari

In 2006, I had a paper that was an intervention study.

Brady Huggett

Uh, that might be the one. Yeah.

Connie Kasari

So we, so we already knew from the work I'd done with Marian Sigman and Peter Mundy here as part of my postdoc. And then a little bit later that kids with autism that are 3 and 4 and 5 years of age have difficulty with joint attention.

Brady Huggett

Yeah.

Connie Kasari

And so at that time the-, there was a lot of interest in what these — what were the — considered the core deficits in kid — young kids with autism.

Brady Huggett

Right.

Connie Kasari

So joint attention was one of those. Um, and then play skills, at least symbolic play was also an area of difficulty, but it didn't seem to be related to their language impairment as much as joint attention was. So I just did a little experimental study of intervention where we randomized kids coming into an early intervention program here, which was based on ABA —

Brady Huggett

Mm-hmm.

Connie Kasari

— mostly discrete trial, 30 hours a week. Kids stayed for about six weeks because that's what insurance would pay for, and we just randomized kids into either joint attention intervention, a play intervention, or they just kept, um, doing the ABA. And the question was whether or not we could improve joint attention and whether that would predict to language.

Brady Huggett

Language. Yeah.

Connie Kasari

And it did.

Brady Huggett

It did.

Connie Kasari

It did. Yeah. 3- and 4-year-olds, it did.

Brady Huggett

Why is that though?

Connie Kasari

Well, at that time, think about this. This was 30 years ago. The ABA programs weren't focused on gesture use, they weren't focused on really play skills. Um, so none of those skills were taught in the ABA program, but theoretically in development for all kids. Kids learned to gesture and to communicate in that way before they learned to speak. So we just focused in on that early developmental, um, set of skills.

Brady Huggett

But is, is the — I mean maybe this is known and I just don't know it, but is the idea that without the gesturing, without when I'm talking to you. Without me being able to say "glasses" and pointing that you don't get the language? It's the gesturing that helps meld that in a child's mind.

Connie Kasari

The gesturing and the, and the [crosstalk] and the communication with — Yes, the word, but also the communication with the other person.

Brady Huggett

Uh-huh.

Connie Kasari

Being engaged, and that's actually what we found was so important from that first study was that the parents would drop their kids off at 8:00 a.m. and they'd come back at 2:00 and pick them up. So they weren't part of our intervention. I had graduate students doing the intervention. Um, and so, but we had the parents play with their kids before we started and then at the end of the six weeks and then, you know, in the follow-up.

Brady Huggett

Yeah.

Connie Kasari

And so parents didn't know if they were getting the joint attention or the, you know, they didn't know that much about it, and yet they're responsive to their kids. So they responded in ways to their kids and their kids were developing these skills. And what was interesting was that both of my experimental groups, play or joint attention, parents were engaged with their kids longer than the kids in the — in that just continued ABA. So that ability to engage that interest, that ability to communicate with another person increases if you can stay engaged.

Brady Huggett

So that's why there, there's a jump in language, you think.

Connie Kasari

Well, we've now shown that that is a, a good mechanism of, of this particular intervention approach. Mm-hmm. So that in fact, if you get JASPER, and we're trying to improve your initiating of joint attention, because we know that predicts to language that the mechanism is joint engagement.

Brady Huggett

Huh.

Connie Kasari

The longer you stay engaged.

Brady Huggett

So I actually wanna ask about JASPER too, right? So just can you take me through what — because it, it sounds like I was reading the description, it sounds a lot like ABA in a, in a way, um.

Connie Kasari

Mm-hmm. Right? So when you read on paper, all interventions kind of sound alike, right?

Brady Huggett

Yeah.

Connie Kasari

You're working with little kids, you're trying to increase skills or you're trying to decrease negative behaviors, you know, challenging behaviors. So on paper, they probably do sound alike, but I think JASPER is uniquely different in some very particular ways. So we are very developmental in that we assess kids and we think about that kid who's right, sitting in front of you and what it is that we need to — What gaps in development we need to fill in. And because all little kids are learning to, um, to joint attention and requesting skills and communicate with their social partner —

Brady Huggett

Mm-hmm.

Connie Kasari

— they're learning to play. So those are the skills we're focused on. Um, but we take a very developmental approach to that. At the same time, we're gonna use behavioral strategies, too. So if a child has a challenging behavior, we're gonna address those in the same way that somebody doing DTT [discrete trial training] would. Right. They're gonna look at the function of the behavior, and they're gonna try to figure out what they're gonna need to do.

Brady Huggett

Yeah.

Connie Kasari

Before the behavior hap — to prevent the behavior from happening. So in that sense, um, or similar, but whereas discrete trial and I think when people say, "ABA" in the negative connotations, that's what they're talking about. Um, whereas discrete trial is doing these kind of, um, discrete skills. We're trying to connect them all together. So we're —

Brady Huggett

It's sort of more holistically, I suppose would you say? Yeah.

Connie Kasari

Yes. More holistically, more like real world.

Brady Huggett

Yeah.

Connie Kasari

How kids really play.

Brady Huggett

Yeah.

Connie Kasari

So that's what we think about.

Brady Huggett

Uh, I mean, do you think it's any more effective?

Connie Kasari

It is more effective in that —

Brady Huggett

So why don't — you know, why don't we try things like JASPER all over the world —

Connie Kasari

Well.

Brady Huggett

— instead of ABA?

Connie Kasari

Well, both can be effective. So with those first studies, you know, adding in joint attention and play was in contrast, in contrast to just discrete trials.

Brady Huggett

Yeah.

Connie Kasari

And so adding in teaching those skills matters. So could you teach those same skills using DTT for some kids? Absolutely. For other kids, no. So I think we have to get to the point where we think about this individual child sort of, um, that moderation, which kids are gonna benefit from which intervention best. And we need to stop thinking about kind of horse races. This intervention's better than this one, because at, at a particular age, a developmental age or situation, DTT could be better than JASPER.

Brady Huggett

Mm.

Connie Kasari

And we've actually have some data on this. So again, I think we wanna think about the, the method, the approach within an individual child.

Brady Huggett

But the — so the hard part I think is that when, right, so ABA is now, I mean, it's still not readily available in parts of the country. They're slowly growing it, etc. But that is not all that individualized. I mean, it's meant to be, but right now it's sort of like you get a diagnosis, you go off to ABA —

Connie Kasari

Uh-huh.

Brady Huggett

— and that kid is sort of at the mercy of whatever that business is doing that day. Like, I don't think they're getting quite the individual attention that you're describing. And I don't know how that happens at scale.

Connie Kasari

So you've just put your thumb on the problem. It's not ABA that's the — necessarily the problem; it's the implementation.

Brady Huggett

Yeah.

Connie Kasari

And it's true, we need a, a workforce that has many tools in their toolbox and are more sophisticated. But when you have a whole industry that's only teaching one approach, that's all you're gonna get. So then it doesn't feel like it's that individualized.

Brady Huggett

Yeah.

Connie Kasari

So that it's more in the implementation than it is the problem of the interventions. I started off doing, um, you know, building JASPER, but we started with discrete trials at the table and then generalized to the floor in that first study. I dropped out the discrete trial as a separate thing, um, for a number of different reasons. One is we — the next study I did was with parents, and I didn't want parents doing discrete trials. It didn't feel normal.

Brady Huggett

Mm. Right.

Connie Kasari

Natural.

Brady Huggett

Right.

Connie Kasari

Um, but there are times when kids need a little bit of repetition to learn a skill. And I don't think there's a problem with that. But when you use it, sort of the timing of that is what turns out to be important.

Brady Huggett

When you use the repetition, you mean?

Connie Kasari

Yes.

Brady Huggett

And you say timing, you mean like in their development, their, their age?

Connie Kasari

It could be in their development, but also in the context of intervention. So I — you know, I see a lot of kids who are minimally verbal.

Brady Huggett

Mm.

Connie Kasari

Who already are having very slow progress. They're 4 and 5 and 6 and still not speaking with words, or not very many.

Brady Huggett

Yeah.

Connie Kasari

And so sometimes they need a little bit more direct instruction. So I think of those repetitions as direct instruction, letting them know what the expectation is and what we want. But then it's important that you connect it within context, which is what JASPER does. How do you play?

Brady Huggett

Right.

Connie Kasari

It's, it's not a discrete skill.

Brady Huggett

Right.

Connie Kasari

It's, it's a connected set of behaviors.

Brady Huggett

So the, the like all the problems that ABA has as far as scaling and getting individual treatment, that would be twofold if you were to try to implement JASPER —

Connie Kasari

Oh.

Brady Huggett

— because it's a bigger —

Connie Kasari

Yeah.

Brady Huggett

So, so, so how, how do we make something that is actually — that has proved to be useful to children, how do you actually implement it at a large scale?

Connie Kasari

Yeah. I know everyone wants everything at a large scale. And of course that would be something we need to think about. But at the same time, do you want something that — so autism is a very complicated condition.

Brady Huggett

Yeah. Here, let — lemme back up. 'Cause I don't — I — maybe what I shouldn't have said is large scale —

Connie Kasari

Uh-huh.

Brady Huggett

— but make it accessible for people who need it.

Connie Kasari

Yeah. I think we do wanna have a lot of different interventions that are accessible to a lot of intervention, uh, to a lot of individuals.

Brady Huggett

Yeah.

Connie Kasari

At the same time, you just don't want somebody coming off the street and be able to do this. You want a really skilled workforce.

Brady Huggett

Right. That's also a part of the problem with ABA.

Connie Kasari

It is a problem.

Brady Huggett

Yeah.

Connie Kasari

It's a problem across all of our interventions.

Brady Huggett

Yeah.

Connie Kasari

So I don't want somebody doing surgery on me that learned in a weekend.

Brady Huggett

Yeah.

Connie Kasari

And so how do we — so again, I think we start at the top. How are we teaching people to be, you know, any — in any profession? We have to be, I don't know, more skillful in the ways in which we teach them to go out and to do their work. And we need people to be open-minded and to ask questions and to collaborate. So that's kind of the first thing. We shouldn't have a, a lot of rigid people going out and teaching children who are also very rigid.

Brady Huggett

Right, right. Um, I wanna ask this because when we think about your career, how long you've been doing this and how long you've been in this lab and all the things that you've seen. Like the, the field has changed incredibly. The description of autism has changed incredibly.

Connie Kasari

Yeah.

Brady Huggett

And I'm wondering how you feel about, like, when you look at the research that was done 20 years ago, are there things that you wouldn't do today or that you —

Connie Kasari

Mm.

Brady Huggett

— you know, because the field is changing, and you understand autism better than you did in 1997, for instance.

Connie Kasari

Um, well, there's certainly words I wouldn't print anymore.

Brady Huggett

Yeah.

Connie Kasari

I mean, I have titles of papers that have “mentally retarded” in the titles.

Brady Huggett

Yeah, yeah.

Connie Kasari

I wouldn't use those anymore. I don't feel that I've done anything, uh, particularly, uh, abusive or negative in my work, 'cause I've always been sensitive to that. I've always had a del — developmental lens, on the questions that I ask. And I think that the, the early work that we did — so even as a postdoc, the sort of issue of individuals with autism not wanting to, you know, interact with other people or wanting to be alone, we knew that not to be true. And we published studies where we said that is — this isn't true.

It's not that they don't want to, it's that maybe it's the understanding of the context. And so to help people is to help them to understand different contexts and nuances.

Brady Huggett

Yeah.

Connie Kasari

So I, I feel like we've learned from that. I do feel like we repeat the same studies over and over because our — the people that are coming into the field now don't read the studies from 30 years ago.

Brady Huggett

Really? Oh, because they think they're outdated.

Connie Kasari

Yes. They only go back about 10 years.

Brady Huggett

I see.

Connie Kasari

And so it feels like we're just repeating some of the same studies that we had already done before. So I guess —

Brady Huggett

Yeah, that's not progressing the field. Yeah.

Connie Kasari

No, it slows our progress in some ways. Um, I still think there's a lot of things that we need to do in the future. And actually, I don't just do JASPER, and thank goodness I don't.

Brady Huggett

Yeah.

Connie Kasari

I do multiple kinds of interventions because as kids grow, you learn new things and you wanna try — or you wanna address new problems. So that has been really interesting to me. And that — and the fact that I go into schools or, you know, I'm looking at kids in different contexts.

Brady Huggett

I see. OK. And I — we talked about this before, but I also wanna ask 'cause this is a — it's on the same theme of — one of the things about autism that I find fascinating is that it has changed so quickly in 30 years. Um, both that's in neurodiversity movement. It's the concept of what it is. So I, I think that's fascinating.

And you have seen that, you know, up close and personal, so I wanna ask about INSAR too, because that has been like a magnifying glass almost for some of the issues. You want these kinds of presentations, you also want these kinds of presentations. You want these kinds of people to attend INSAR, you also want these kinds of people to attend INSAR. So as the, like, current president, how are you managing to do that?

Connie Kasari

Well, first and foremost, we think of INSAR as the science of autism. So it's research.

Brady Huggett

Yeah.

Connie Kasari

It's not just clinical practice or service. So it is always about science. There's a lot of different kinds of science, and we have progressed in all areas of society by bringing in all different kinds of scientists. And I think that we want INSAR to reflect that broad view of science. And it's not for one group of people from, you know, any area to say that we don't accept this kind of science.

Brady Huggett

Yeah.

Connie Kasari

We don't accept sham science —

Brady Huggett

Right.

Connie Kasari

— or, um, harmful science. Now, people have different opinions about what is harmful. Um, but again, there's a broad view of science here, and we do wanna be scientific because there are other organizations that can — that address, you know, more ethical issues or social issues or service issues, you know, parent organizations or autistic individual organizations —

Brady Huggett

Yeah.

Connie Kasari

— and they all have an important role, but our focus is really on science.

Brady Huggett

So, but the science has broadened over the years?

Connie Kasari

Certainly, because as scientists have broadened and have understood different aspects of autism, but also different methodologies. And so yes, you can bring all of those together. I mean, there's never enough in any one area for any one group. They're always complaining. Like I heard a lot of people wanting more on education and on schools, and we don't have as much in INSAR as we would like.

Brady Huggett

So I think that's my question. So then are you — when you hear that, are you thinking, “Well, OK, let's try to get more in education then.”

Connie Kasari

Yeah. I mean, I think that we're always wanting people to come together, but unless people are around the table, you, you don't hear their voice. And educators, school folks, are often not around the table for any kind of autism research. I've been saying this for 30 years. Where are the educators? And, and the fault lies on both the sci — the sort of medical science part and the school part.

Brady Huggett

Where are the educators?

Connie Kasari

Well, they're doing their own thing.

Brady Huggett

They're going to education seminars.

Connie Kasari

Yeah. They're doing their own thing, but we need to bring them together. So when you have NIH coming together with workshops, we need to have educators around the table.

Brady Huggett

Yeah, I had not considered that. That's a good idea.

Connie Kasari

Yeah, they have an important voice in all of this.

Brady Huggett

So, but that's not — but you're saying also that's not particularly INSAR's focus, but you're saying they should come and listen and —

Connie Kasari

Well, no, they could bring in educational research.

Brady Huggett

Oh yeah, that's true.

Connie Kasari

Any kind of science is welcome. Precli — preclinical animal research is welcome, as well as sociological kind of research. So to me, those are, you know, different ends of a spectrum.

Brady Huggett

Yeah. I just — I mean, I had this feeling that, um, you know, the criticism would come, but I don't think that they were aware as I wasn't really until I asked you, um, how much thought goes into planning it out?

Connie Kasari

Yeah. And a lot of thought goes into planning it out, but in also in sort of balancing and magnifying certain voices. So, [chuckles] last year was my first year, and of course, we were in Texas. And Texas came out with some very unpopular, you know, policy positions that upset a lot of folks.

Brady Huggett

Yeah.

Connie Kasari

Uh, and rightfully so, and so — but we had planned to go to Austin for like five years. So these are things that one doesn't just shift —

Brady Huggett

Walk away from — yeah.

Connie Kasari

Yeah, you can't just shift. So instead we, we gathered, and we did have these civil discourse conversations where we brought people together with the idea that you bring people around the table to discuss these really kind of difficult —

Brady Huggett

Contentious issues, yeah.

Connie Kasari

— conversation. And they were great.

Brady Huggett

They were great.

Connie Kasari

Yeah. We had two. Were you there?

Brady Huggett

No, I was in Austin, but I wasn't, I wasn't at —

Connie Kasari

Oh, you didn't come?

Brady Huggett

I was in — I was at the meeting, but I wasn't at — I think what the specific moment you're talking about.

Connie Kasari

Oh yeah, the civil — we had two on Thursday.

Brady Huggett

Yeah.

Connie Kasari

One was on LGBTQ youth with —

Brady Huggett

These are the SIGs [special interest groups] we're talking about?

Connie Kasari

The — no.

Brady Huggett

No.

Connie Kasari

The SIGs are also going on, but these were separate. They were civil discourse conversations.

Brady Huggett

Uh-huh.

Connie Kasari

So we had one on LGBTQ plus youth and one on, um, ethnic-racial diversity.

Brady Huggett

Yeah.

Connie Kasari

Two important areas for us as researchers, but also we're contentious in the, the state. Next year we'll be in Sweden. And we're gonna have civil discourse conversations and we're looking to the membership to, to raise some issues. They've already raised a couple of issues and one of those is bringing together — I don't know if this is one we'll do, but it is bringing together parents a profound autism, um, children —

Brady Huggett

Yeah.

Connie Kasari

— or adults and the neurodiversity community so that they have a conversation together. Um, because there seems to be tension there.

Brady Huggett

Yeah, you're right.

Connie Kasari

And it's unclear why we should have that kind of tension.

Brady Huggett

Yeah. Yeah. Uh, yes. Somebody told me, um, that there's actually an area between those two groups that they are focused on, and they both would like to see more research at the place, like INSAR focused on present-day for the — not like genetics, but like, how can my child get through the day?

Connie Kasari

Right.

Brady Huggett

So those two groups are actually focused on that. They just don't necessarily sometimes know it, I think.

Connie Kasari

Yeah. They're — yeah. They're both focused on the same sort of outcome. But one takes a, a longer time to get to the immediate issue.

Brady Huggett

Yeah. Yeah.

Connie Kasari

And I think we have all of that happening at ISAR. There are, there are certain researchers that are focused on families and present-day and challenges. We've had — we have a SIG on challenging behaviors. Yes. Getting through the day and not having my child hospitalized and —

Brady Huggett

Yeah, yeah.

Connie Kasari

— is really important. And the idea that some people are minimally verbal or non-speaking, and how do we amplify their voice? And so the people that can amplify their voice the best are the family members around them. Um, but the family members don't think that the neurodiversity community speaks for them, and the neurodiversity, uh, movement doesn't see the parents speaking for them. And so really we have to get together and talk about those common areas of where we do speak the same language.

Brady Huggett

Yeah. I mean, I would like to go to that. Maybe I'll make, make that a priority because I think, honestly, I also think that if you get people in the room, it's gonna be better than what you see online. I mean, online amplifies all the tensions that we have.

Connie Kasari

Well, online too. You can hide or mask behind that sort of —

Brady Huggett

Avatar.

Connie Kasari

Yeah. And so, I don't know. I, I actually don't read it.

Brady Huggett

Good.

Connie Kasari

Don't listen to it.

Brady Huggett

You're probably healthier for it?

Connie Kasari

Well, yeah. I don't wanna hear about all the things that I'm not doing or, in doing so —

Brady Huggett

Yeah. Um, I'm, I'm, I'm about done. I wanna ask you one thing. So how big was your school, like your high school?

Connie Kasari

Oh, I mean, I don't know. A, a hundred people maybe.

Brady Huggett

Total.

Connie Kasari

Total.

Brady Huggett

OK. So 25 —

Connie Kasari

Tiny.

Brady Huggett

— 30 in the class.

Connie Kasari

Oh yeah.

Brady Huggett

Yeah, yeah, but what is it about, do you think that, um, when you came across children who were in special ed that pulled you in that fascinating? Was it this concept that they're being left behind and nobody's doing anything about it or —

Connie Kasari

Yeah.

Brady Huggett

— that was it?

Connie Kasari

Oh yeah. Equity, jus — social justice, and I, I still feel that way. I mean, why do we have children on core curriculum, so meaning the same curriculum as a third grader in gen ed —

Brady Huggett

Yeah.

Connie Kasari

— but they're in a separate classroom? Does that make any sense? And that still goes on today. I don't understand why kids on core curriculum are in separate classrooms. I don't understand always why kids on alternate curriculum are in separate classrooms. There are certainly places where kids can come together in the morning for morning meeting and maybe they — if you're on an alternate curriculum, you have to go out and have separate, you know, instruction —

Brady Huggett

In class or something. Yeah.

Connie Kasari

Right. But there are many times during the day where you should know the other kids in your class and the other kids in your class should know that you exist.

Brady Huggett

Yeah. But why — I'm like, I'm curious as to, I don't know that everybody would feel that way though, but for some reason, you did feel that way.

Connie Kasari

Yeah.

Brady Huggett

And do you have any idea why, why that is? I mean, is it, was it part of your family, or is just something in common that — ?

Connie Kasari

Probably. Probably. I mean, we had all kinds of hired hands that had disabilities. And I mean, I can remember very salient, um, you know, con, contact with people. I didn't have people in my family with disabilities, although, although my father had, um, I think five siblings, and one died when she was 12 of a heart —

Brady Huggett

Mmh.

Connie Kasari

— disorder. And much later I saw pictures of this little girl; she had Down syndrome.

Brady Huggett

Oh, I see.

Connie Kasari

Wow. [chuckles] So I did have —

Brady Huggett

And, like, that's not even part of the family history.

Connie Kasari

No. Well, they never mentioned that she had Down syndrome.

Brady Huggett

Yeah.

Connie Kasari

Maybe they didn't know.

Brady Huggett

Yeah.

Connie Kasari

I don't know.

Brady Huggett

Yeah.

Connie Kasari

Um, but clearly she had Down syndrome, but, but I didn't grow up with, um, siblings or with family members who had disabilities, but I think my parents, my family always, you know, cared for other people and were inclusive and, you know, I lived in a farming community, so everyone was pretty inclusive.

Brady Huggett

And something about that just, I don't know, something about that bothered you. You thought these people are not given the same attention as everybody else, not given the same resources as the other kids, and there's no reason they just happened to be born differently.

Connie Kasari

Right. Although, I think they were in my class, so they were given. So maybe I, I don't know. Maybe I just —

Brady Huggett

Yeah, so you — Yeah, they weren't off in the basement as you were saying.

Connie Kasari

They weren't off in the basement. Yeah. But you know, trying to reach them to figure out how they could learn is still fascinating to me.

Brady Huggett

Yeah.

Connie Kasari

Yeah.

Brady Huggett

Good. OK. That's it.

Connie Kasari

OK.

Brady Huggett

Thank you.

[transition music]

Brady Huggett

There you go. That is Connie Kasari, a very nice woman, you know. Obviously a big contributor to this field. Thanks to Connie for having me into her space to record, and I think that if you ever get a chance to sit down and speak with Connie Kasari, you should do it. I think, um, I think you'll enjoy it. OK. This podcast will be archived at spectrumnews.org. The

next episode will be out July 1st. You can subscribe to “Synaptic” wherever you find your podcasts. And if you like this, and if you are so inclined, you can rate and review it. That does help other people find the program.

If you haven’t, you can go back and listen to the inaugural episode of “Synaptic,” which featured Cathy Lord; that is found in our archives. A reminder that you can find us on Twitter where our handle is @Spectrum. You can use that to tell us what you thought of this podcast or actually anything else that we do here at *Spectrum*. Our theme song was written and performed by Chris Collingwood, and that’s it. I will talk to you on the next one, and I’ll let the music play us out.

[end theme music]

Connie Kasari

Um, I became a professor in 1990, but I was here in 1985 —

Brady Huggett

For your NIH fellowship, yeah.

Connie Kasari

— for my post-doc. Yeah.

Brady Huggett

OK.

Connie Kasari

So you did a little research, huh?

Brady Huggett

Oh yeah, of course, of course.

Connie Kasari

Oh my goodness.

Brady Huggett

I’m not gonna come in here and be blind. [laughter] That would be a terrible interview.

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