

## The power of international neurodivergent collaborations: Interview with AutCollab's Jorn Bettin

November 14, 2022

[Intro music: Jazzy synth pop music]

**Anne:** You're listening to Noncompliant, a Neurodiversity Podcast. I'm your host Anne Borden King. Today, I'm speaking with Jorn Bettin.

Jorn is an autistic anthropologist by birth and a knowledge archeologist by autodidactic training. He has a background in Mathematics and enjoys working closely with domain experts in transdisciplinary contexts. His current work focuses on the co-design of a new community-oriented and patient-centric model of care. Jorn has co-authored several books on creative collaboration and model-driven product line engineering. He is a trustee of the Autistic Collaborative Trust (or [AutCollab](#)) – a global mutual support hub for neurodivergent individuals and ventures. He is also part of the [Design Justice Network](#), regularly working with those who are most adversely affected by design decisions — about healthcare service delivery, new technologies, and the planning of communities. We're connecting today across 17 different time-zones from Aotearoa New Zealand to Toronto, Canada; and I am so excited to have Jorn on the show.

Welcome to the show, Jorn.

**Jorn:** Yeah. Thanks Anne. Many thanks for your invitation. I am looking forward to this conversation.

**Anne:** That's great. Can you tell us how you became interested in autistic advocacy?

**Jorn:** When I learned about autistic ways of being and seriously started to suspect that I might be autistic around 12 years ago, I had many online conversations with autistic people, and then I was appalled to discover all the dehumanizing myths and misleading stereotypes about autistic people that were presented as facts by the so-called autism experts, couched in the language of the pathology paradigm.

At the time the stigma associated with being autistic was such that most of the online conversations amongst autistic people were confined to anonymous online forums. And then I

realized that I had built my entire life around autistic people, going right back to the very few children that I connected with at school, and right through to the people I ended up working with in the abstract domain of designing visual domain specific languages.

That's why I usually refer to my work as knowledge archaeology, it involves a lot of creative collaboration around whiteboards and development and validation of mathematically precise, visual concept graphs that can then be used for advanced form of automation...but interestingly also for creative play and high-fidelity knowledge transfer between humans.

Now, one of the persistent negative stereotypes is that autistic people are not good team players and are poor at collaboration. I'm basically on a mission to demonstrate the opposite. And, this is what prompted me to create the autistic collaboration website in 2017.

Collaboration can take many forms and different people have different needs and preferences. Autistic people-- we learn and play differently and only have a limited, if any, interest in competitive social games; that makes us different. We communicate and enjoy ourselves by sharing information and knowledge and not by negotiating social status. So that's how it [AutCollab] started.

**Anne:** Wow. So you've been doing this since 2017 and how has the situation been evolving in Aotearoa New Zealand for autistic people and neurodivergent people in general? What's the kind of trajectory that you've seen so far as you've begun doing this work?

**Jorn:** Mm-hmm. Yeah, for the most part, the situation for neurodivergent people in Aotearoa New Zealand is very much the same as it is in other parts of the industrialized world. There is significant stigma attached to openly identifying as autistic, and the same holds, of course, for a range of other labels that are connected to the DSM. And it's I think no coincidence that in our industrialized civilization quotes such as "life is not fair, get used to it" are commonplace, and that the Autism Industrial Complex is a rapidly growing, global, multi-billion dollar industry.

If you ask me, perhaps the biggest damage caused by the cultural bias in the DSM is the implicit assumption that deep down most humans are competitive rather than collaborative. And, as long as we rely on the DSM for assessing who is "normal" and what behaviour is acceptable in our society, we are legitimizing WEIRD tools of oppression...so, WEIRD in this case stands for Western, Educated, Industrialized, Rich and Democratic.

Now, in te reo Māori, the local indigenous language here, the word for ADHD for example is *aroreretini*, which literally means "attention goes to many things," and the te reo Māori for

autistic is *takiwātanga*, which literally means “in their own time and space”. Both are non-pathologizing terms. And, these wonderful terms are part of the language of enrichment which was developed by a te reo Maori person called Keri Opai and in his words, te reo Hāpai, this new language is about enriching language, including words of great power in te reo, from a strengths based...Māori world view.

**Anne:** Wow.

**Jorn:** And this is a wonderful development, given that the language of enrichment is actually based on the chunking of pathologizing concepts and the DSM. It is also worthwhile pointing out that prior to the arrival of Europeans, neurodivergent people here were not explicitly labeled or pathologized at all in Māori societies. And this underscores what I was saying earlier that exporting the DSM is a form of neo-colonialism.

**Anne:** Yeah. I want to back up for a minute to just define the DSM for anyone listening who might not know about the Diagnostic and Statistical Manual that’s used by psychologists and autism professionals, pediatricians, doctors. It’s a book that was developed to kind of create these different names and pathologies for different forms of neurodivergence and, so that’s what we’ve been kind of referencing back.

It’s a product, I would agree, of colonial practices where this sort of institutional racism and the development of the institutions that seek to contain and control people under this industrial-capitalist model and now we are broadening our definitions of what autistic culture is and looking at other types of ways of defining ourselves as opposed to just being pathologized. It’s very interesting to hear that that’s happening there. It’s certainly happening here in Canada as well, and Black, Indigenous and People of Colour suffer the most under that older DSM type-model that’s still being used today.

It seems to me that a big part of our liberation that is unthinking not only the medical model-the institutional model of autism, but also the colonial model generally. I’m wondering what your thoughts are from the perspective of what’s happening in Aotearoa, in terms of decolonizing in that sense.

**Jorn:** Autistic ways of being and other uncommon neurological variants cannot be understood without the social model of disability, and in the context of neurology, I like to introduce the people to the social model of disability via two concepts: neuro-normativity and neurodivergence.

Now, neuro-normative people are all those who are considered to be culturally well-adjusted in their local, social environment and it's obvious that if you take a neuro-normative person and transplant them into an unfamiliar cultural context, that they would likely be perceived as a stranger with odd, unusual and perhaps inappropriate ways of interacting with others.

And this illustrates that there's not one way of being neuro-normative and that neuro-normativity can only be defined relative to a particular culture. And now, consider all those who have grown up in a particular culture, but who fail to meet local, social expectations and are also seen as having odd, unusual and perhaps inappropriate ways of interacting with others. Those are all the neurodivergent people in a given social environment or culture. And now, it becomes obvious that just as neuro-normativity, neurodivergence can only be defined relative to a particular culture. And, so with these two concepts we can now look at the DSM which you've just explained (and I refer to the DSM as the Devil's Sadistic Manual)...and the role that it plays in industrialized societies. Knowing how the pathologizing definitions within the DSM have come about largely reflecting the consensus of the culturally, well adjusted, old white men within WEIRD societies.

**Anne:** Mm-hmm.

**Jorn:** we can see that all the labels within the DSM are the product of a particular culture and this culture frames and pathologizes autistic ways of being and many other neurodevelopmental differences as disorders.

The project really of exporting the DSM to other countries is [sigh] in a way which is for example being done by the Autism Industrial Complex with respect to anything related to autism...this is a form of neo-colonialism. the DSM goes hand in hand with the definition of normality in the industrial era which is based on the metaphor of society as a factory, and on the metaphor of people as machines. Our social norms have been shaped by these metaphors to a far greater extent than most people are able to comprehend without an in-depth explanation. Does that make sense?

**Anne:** Yes, absolutely.

**Jorn:** I would like to dive deeper into how this relates to colonialism. There are many similarities between the current role of the DSM and the way the official language of the British Empire was used to systematically marginalize and dehumanize indigenous populations, and to replicate and perpetuate British/European imperial structures of power. My critique of the

establishment goes beyond the Autism Industrial Complex. I think we need to question the whole philosophy and worldview that is baked into the DSM.

Here in Aotearoa, the legal foundation of the country is the treaty of Waitangi, supposedly in “partnership” with the British crown. Now, this treaty is a classic example how language was and is used to intentionally mislead people, often using subtle techniques that only become apparent over time. Furthermore, the treaty exists and was signed in both English and in te reo Māori, but for many decades only the English version was considered to be authoritative. The two languages are so different that there are some formal British legal concepts that have no equivalent in te reo Māori and conversely that there are many concepts in te reo Māori that are important for the culture that have no equivalent in English; and this was very conveniently brushed under the carpet. And it’s only over the last, say, 20 years that Māori scholars have done some excellent ground-breaking work in terms of in-depth analysis of the legal-linguistic manipulations.

And, without going into the details my point here is the DSM is best understood as a symptom of a sick society rather than as a document that is somehow culturally neutral or that has any kind of divine or scientific legitimacy by sheer existence.

Just like in Canada, in Aotearoa the Māori language and many aspects of Māori traditional knowledge have been actively suppressed for over a century. Māori children were not allowed to speak te reo at school and for many years te reo was not taught in schools. And this has only changed very recently. Today, the cult of European superiority and imperialism is very much reflected in the WEIRD, neuro-normative pathologization of neurodivergent people.

Many neurodivergent Māori people are locked up in prisons without access to adequate support and without access to diagnostic services that would acknowledge their need for assistance rather than incarceration. I mean, luckily here, prisons are not as big of money-making machine as they are in the U.S. but our incarceration rates are disturbing as our rates of domestic violence that result from poverty, deprivation and systemic discrimination. And the primary social exclusion criteria today is whether a person is functional within the factory model of society. Whether economic utility can be extracted either through labour within a profit driven enterprise and if not then via pathologization which ensures busy-ness and profit via the Autism Industrial Complex and other industries.

**Anne:** Yeah, I want to dive a little bit more into that concept of the Autism Industrial Complex because it relates so much back to what you’re talking about in terms of colonialism and what’s happened with the Māori and even happening now as well, obviously today – this isn’t history

that we're talking about. This is happening to indigenous people around the world. The ABA industry is trying to get more of a foothold not only in Aotearoa but also on the continent of Africa, on the continent of South America. They're trying to parachute into Indigenous northern communities in Canada and they have a very specific, very, very troubling view of how to contain and control autistic people.

I was hoping we could talk a bit about the ABA industry. Of course, it's very entrenched in Canadian culture and I understand it's trying to get more of a foothold there as well. I'm wondering what the response is from communities to this movement of the ABA industry to try to become entrenched in funding and policy and medicine there.

**Jorn:** Yeah, this is a good question, and you're right. I mean ABA here in this country doesn't yet have the level of funding that it has for example in the US, so if say parents want to have something like ABA the level of government support for that is, luckily, limited...but then what the local ABA industry is doing here is effectively (because of the more limited resources) focussing on "teaching parents" to educate or engage with their children via ABA techniques which is really very disturbing.

In September 2021 we presented our submission to the government's Conversion Practices Prohibition Legislation Bill, and this was, I think, quite well received so from the perspective of the Autistic Collaboration Trust.

We are counting the days, hopefully, until all forms of conversion therapies are banned in Aotearoa but this might be a few years away. The submission in our argument that all forms of conversion therapies must be banned was well received, interestingly, or encouragingly by several MPs. I think it's a question of time and autistic perseverance. Our hope is that within the next few years we can get the government to honour its commitment to banning these practices and also its commitment to human rights which includes all the rights articulated in the [United Nations] Convention on the Rights of Persons with Disabilities which our government ratified in 2008.

Now, of course, like in other countries, parent-led autism organizations continue to have at least one foot in the ABA camp, but our campaign and I think local autistic activism has forced them to admit that the topic of ABA is controversial to say the least. I think inviting Aotearoa to ensure ABA doesn't get as entrenched as it is elsewhere and that we can basically turn the curve around in the other way and there are some signals that are looking really good, but as you outlined, I mean, if we look further afield it's really, really scary to see how this industry operates, and how the pseudo-science of behaviourism continues to propagate itself.

And I think this comes back to the fact that actually our economic ideology, the economic religion of neoliberalism is so tightly coupled to behaviourism, you actually can't separate the two. The Western education system, if you look closely, is a form of ABA-lite, and effectively what ABA is doing with autistic people they're saying "oh, all right, these children don't seem to respond to light versions of behaviourism so we just have to crank up the dial very significantly and let's see whether we can't get them on board." That's how I describe ABA.

[19:50]

**Anne:** Yeah, definitely and they are [also] instigating more and more ABA type practices in prisons as well, which just really follows a natural narrative of what ABA is. Some people are even trying to suggest that ABA, in the form that we know it so well, should be implemented more and more into classrooms. But, like you said there's already a version of ABA behaviourist style training that happens in classrooms every day.

I wanted to pivot a little bit over to the Global Autism Project and some of these other projects that actually take a missionary... they'll even call it a *mission* – a missionary style approach to bringing ABA to what they would refer to as kind of the "uneducated masses" in these other countries. They send these BCBA's off on these missions, to educate and supposedly offer tools to communities. It's very, very hard to combat, and I can see that it's even happening there, but I think that it leads back to this divide--in terms of how people are viewing autism.

Put very simplistically, if you look at autism through the DSM model and the medical model of autism, and the ABA model of autism, it's about fixing the child to fit into the environment, and if you look at it from more the social model of disability, it's really about making some changes to the environment and adapting the environment so that everyone can fit in.

I guess I'm relating that back to some of the work that you do around design justice which I'd love to hear you talk about, in terms of universal design and as an alternative to what we've just been talking about-- making design changes so that people can be included and feel more welcome. And systems like ABA would fall to the side if we incorporated design justice.

**Jorn:** Yes. The problems are very much systemic and as we're discussing here go far beyond ABA. The problem is really behaviourism and behaviourism. From a scientific perspective, I mean any honest scientist would have to admit that the whole enterprise of behaviourism is not scientific. It's a kind of religion. It's an ideology. And we constructed entire economic systems around this type of ideology and we're basically confusing this ideology or religion with something that can be justified--and it certainly can't be justified by any kind of scientific rigour. There is none to this. People know this. And it is incredibly disturbing to see how ABA is

exported to so called less developed countries. And it rides on the back of Western industrialized economic paradigm.

Now, design justice... this concept is squarely about the relationship between design and power and a growing community of designers, technologists, scholars, educators and community organizers who have come together to avoid reinforcing all forms of interlocking systems of structural inequality, including algorithmic injustice in the online world. And, design and disability justice go far beyond universal design in explicitly prioritizing design work that shifts advantages to those that are currently systematically disadvantaged and disabled. Especially those that are intersectionally or multiply marginalized.

Design justice urges us to make intentional decisions to reduce systemic privilege and power gradients and here you can see how this grades right when you look at our economic ideology, which is more based on the myth of the Invisible Hand...that competition has somehow magically resulted in lifting all boats. I mean the data – everything shows us that this is bullshit and yet we stick to this ideology. So it's no wonder then that as long as people believe that economic ideology they are just prone to then also falling for ABA for exactly the same kind of reasons.

The educational challenge within our population which has been heavily indoctrinated – it's a very big educational challenge. I think this is a generational project.

The Design Justice Network is a wonderful grassroots organization that is, by the way, very active in North America, including Canada. I would encourage autistic people really to participate there, because within that wonderful grassroots movement, you'll find many members who identify as neurodivergent. We actually have a Slack channel there on the specific topic of neurodivergent collaboration.

**Anne:** Wow, that's great. I'd like to link, maybe in the blog, to the Design Justice Slack channel, so that people can find it, if that's all right.

**Jorn:** Yes, yes. I can provide you with links. It would be wonderful to see more autistic people there.

**Anne:** Yeah, we've been focusing kind of on this idea of a person's perceived utility in an industrial society and how that relates to the DSM and the whole defining kind of matrix of like pathologized neurologies, right? And it seems to me that the utility of an autistic person in an industrial society, the fallback and the default of these institutions is that to place most of the-

most of the utility on being compliant, and that's why systems like ABA are so crucial to that model because it's all about making people compliant.

Compliance is the goal and it's seen as a success if an ABA program makes someone completely compliant. That really goes up against this concept of quality of life. I tend to look at it as this divide between "do we care about making people just compliant or do we care about their quality of life?"

And I want to bring that into talking about autistic culture, because I know that's something that you do a lot of work around. This is a resistance to this concept of "hey, as long as we make someone compliant, we've fixed their autism," which is the ABA and the DSM model. But, what about another model, where we say where we say, "let's look at what autistic culture really *is* outside of these pathologizing models and then talk about what is it that makes a quality of life for an autistic person and have that be the project of research and the project of advocacy, and the project of autism services." What are your thoughts about that?

**Jorn:** Yeah, autistic culture is such an important topic and you can see how it relates to what we talked about earlier with neurodivergent collaboration – forms of collaboration that emerge and evolve amongst neurodivergent people...and this is actually going on as we speak, right? I mean, this is one of the things that has been enabled with the internet, and it's important to realize that this is not something that can be advanced via research, no, this is something that happens at the grass roots level. This is lived experience- every day this is happening much faster than research, so yeah, you can, of course try to track some of what's going on in terms of research but academia that will always lag behind by at least a decade...

**Anne:** Yeah.

**Jorn:** ...and the really interesting thing is happening on the ground. In order to get genuine traction and support for the neurodiversity movement within mainstream society, it is important that all neurodivergent people and especially autistic people and all those who are discriminated against in terms of lacking protection of human rights, that we are recognized as minority groups. As groups of people who share commonalities in their way of being in the world who tend to live and work together and who have specific cultural practices, like all other minority groups. And so far, within mainstream society, autistic people are still perceived as isolated individuals with the assumption that many of us are loners and with no interest in interacting with others and that those who do interact with others have similar life goals as the neuro-normative people around us, and we all know that that's far removed from the truth.

Autistic people for example choose autistic life partners at rates that are ten times higher than by random choice.

[30:22]

**Anne:** Hmm.

**Jorn:** In mainstream society, people don't understand how autistic people support each other. How we love each other and care for each other in ways that go far beyond the culturally impaired neuro-normative imagination. And, I think everyone is familiar with the saying that it takes a village to raise a child. Now, the autistic translation of this saying is for an autistic person, it takes an extended autistic family to feel loved and alive. And, unfortunately, most autists are not born into healthy autistic families, and therefore we have to co-create our families in our own space and time. Now, in a healthy culture, autistic children are assisted in co-creating their unique autistic families but in our "civilization" this cultural knowledge has been lost and is suppressed.

In many indigenous cultures, children with unique qualities are recognized and they are given adult mentors with similar unique qualities and grow up to fulfil unique roles in their local community, connected to others with unique knowledge and insights and perhaps even in other communities. And if we are embedded in what I refer to as an ecology of care, we can thrive and share the pain and the joy of life.

For the last ten years, our small company has been operating what I refer to as the NeurodiVention model. Now, I need to define this. NeurodiVenture is an inclusive, non-hierarchical organization operated by neurodivergent people, that provides a safe and nurturing environment for divergent thinking, creativity, exploration and collaborative niche construction...and it is in small, comprehensible – that means human scale social environments where de-powered communication and collaboration is the norm, so you don't have social power gradients, and in those environments it becomes very easy to identify a significant deviation from these norms and any sort of persistent attempts of one person or small group of attempting to wield power over others, that's easily recognized and can be addressed and makes these environments much safer for autistic people.

And in these psychologically safer environments the essential cultural role of hyper-sensitive autistic people becomes obvious for everyone and then what you see happening is that the industrialized separation between "work" and "life" can be seen for what it is. It's a divide and conquer strategy that is designed to perpetuate our dependence on toxic institutions of oppression. Autistic people and other traumatized people should be free to imagine and realize

a world where we don't have to leave behind everything we value in life to go to "work" only to perpetuate what some people refer to as the sanctified institutional bullshit that is killing the entire living planet.

**Anne:** Mm-hmm.

**Jorn:** In te reo Māori, the NeurodiVenture concept, I think translates to what I refer to as neurodivergent whānau and indigenous languages like te reo Māori have important words for concepts that have been suppressed by colonialism. One wonderful word that is still in current use and is actively encouraged here in New Zealand is this notion of whānau, which is an extended family, it's a family group and it's a familiar term to address a whole number of people. It's seen as the primary economic unit in traditional Māori society. And in the modern context, the term is often used to include friends who may not have any kinship ties to other members. That's why the idea of a neurodivergent whānau, or an autistic whānau would be a nice word construction to use. I'm trying to promote this. I think there is an urgent need to patronize autistic collaboration and to co-create healthy neurodivergent and autistic whānau all over the world.

As autists, we depend on assistance from others in ways that differ from the local cultural norm, and this is unfortunately pathologized in what I refer to as *hyper-normative societies*. And, we have to realize that the many ways in which non-autistic people depend on others is considered "normal"... And instead, it's really bizarre that if we depend on other people in ways that differ from those norms that somehow this is not normal or not acceptable. We need to break free from these endless chains of trauma. I mean the... I'm seeing this now via the work we're doing in the health care sector, you know. The level of trauma amongst autistic people, and also the trauma inflicted by the established health care system - It's beyond belief.

**Anne:** Everything you said just rings so true for many of the thoughts that I've been having too, especially this idea of building an extended network and an extended family really of neurodivergent people, which we see happening through the web, that's been happening going back to those groups that you mentioned at the beginning of the interview today, and through social media; with all of its faults it has helped people to really connect.

I wanted to talk a little bit about the health care initiative and what the work that AutCollab is doing.

**Jorn:** We see the health care sector as the key leverage point both in terms of better health care services and safer environments for autistic people of all ages, as well as the urgently needed shift from the pathology paradigm to the neurodiversity paradigm. In many cases, the

first time parents get exposed to the idea that their child may be autistic is when they visit a GP or pediatrician, right?

**Anne:** Mm-hmm.

**Jorn:** And currently these clinicians know next to nothing about autistic culture and hardly anything except pathologizing stereotypes about autistic children and this is reflective of their whole approach and interaction model when it comes to autistic people.

Last year I took a professional development course for GPs and clinicians that had been developed by academic and “autism” experts at a well-known university that I don’t really want to name and shame, but the content of this course--which is intended to equip clinicians to conduct pre-diagnostic assessments--was so out of touch with autistic reality and so much steeped in the pathology paradigm that we decided we have to do something about this state of affairs.

We now have professional development courses for clinicians that have been developed by autistic people based on autistic lived experience, that are framed in the language of the neurodiversity paradigm, and I think that’s where it starts to get interesting, and meanwhile we’re gathering highly disturbing stories of lived autistic experience and shocking statistics about cultural and psychological safety from the health care sector. There’s an autistic research project where we’re investigating this and quantifying it and collecting stories. People can read more about that on the AutCollab website and everyone is encouraged to submit their own experiences. And we actually expand this gathering of lived experience in anonymous form...

...I think also a very good way to collect evidence about the level of trauma that autistic people are exposed to throughout their lives and in all kinds of social environments, often starting within their own families and this is of course something that many parents are very uncomfortable about and don’t really want to hear that, maybe, they haven’t really been treating their children in ways that actually support them, right? Maybe they’ve inflicted some emotional-psychological harm on their children, right? No parent really wants to confront something like this.

[39:54]

I think one of the best ways for autistic people and their genuine allies (which are not always their families) to support our work is to recommend our unique professional development courses to health care professionals in their geography. Our education courses focus on the neurodiversity paradigm, the neurodiversity movement, on autistic culture and on autistic

trauma. And we can talk about these topics in non-pathologizing terms. I mean of course, the traumatic experiences, they leave us with deep wounds and this can have very real mental and physical health impacts, and there we need support. But, autistic ways of being, I don't in any way see this as something that should ever be pathologized.

This is education again by autistic people, based on autistic lived experience and it's focused on re-humanizing autistic people. Allowing us to have high level conversation with doctors and other health care professionals and about autistic ways of being, about our culture, about our different life paths, and about health care needs throughout the lifespan.

We offer, I think, some fairly unique, intersectional, community-powered services around employee well-being that provide employers with independent oversight of cultural and psychological safety by all the marginalized people who on paper are supposed to be actively protected from discrimination and exploitation, and this service relies on externally facilitated anonymous surveys and on making aggregate results available to all participants. to all participating employees as well as the employer. And I think this is a wonderful way of establishing an even playing field between employees and employer, and it's a wonderful opportunity for employers to demonstrate that they genuinely care about staff well-being and are to face potentially uncomfortable data and then to collaborate on appropriate measures to improve the experience level of cultural and psychological safety in the workplace.

And, coming back to health care, we all know that the entire health care sector is ...it's run in a very sort of arcane way with deep silos, with steep hierarchies. These services we also primarily see the initial use case for this in the health care sectors because in the health care sector we also notice that neurodivergent and autistic doctors and nurses and allied health professionals... I mean hardly any one of those people openly identifies as autistic, right? And that I think speaks volumes about the workplace culture that these people have to operate in. And what we'd like to also assist is to connect neurodivergent and autistic health care professionals and they can contact us anonymously, but if we have some information about where to find them, then we can point autistic people in the right direction because many of us, of course, would love to engage with autistic doctors, right?

**Anne:** Definitely. I think it's one of the key places, and it's where we've seen the most change here in Canada. Darla Burrow and I run the Autistic Health Access Project and what we do is we speak to medical students, because until we came into these programs the only introduction that they had in their professional development to autism was a pathology-based model of how to detect and diagnose autism in their juvenile patients. That was it. Then we came in and our message is that "autistic people are your *patients*." And, you know trying to create some subjectivity for autistic people instead of just as objects to just define and diagnose.

What I found that's just so heartening about the project that Darla and I do is that people cannot wait to come to [talk to us](#) at the end of the presentation. The students are very, very interested in this... I think it might be one of the most interesting professional development seminars that they have, because we're a grass roots group, we're coming in, we're speaking very frankly, we're being very specific and identifying barriers very specifically, identifying solutions very specifically and the people that want to do better are just blown away by it, because they don't really get that much of that kind of perspective anywhere without our grassroots efforts, which I think is really interesting.

I want that to relate that to this idea of building international connections, because you're starting – as you have something much larger going. I'm looking at our project which is a smaller, kind of localized ad hoc project. There are projects like the Autistic Health Access Project here - there are projects like that scattered all over the place, but what we haven't really done as autistic advocates enough yet is to coalesce and to find each other and share our resources and our best practices.

I guess I'd like to round out the conversation by talking a little bit about how we build these international connections and start working together more. And what you think are the best ways for groups from different socio-political, or geographic backgrounds to connect and communicate so that the autistic communities can work together more.

**Jorn:** Mm-hmm, yeah. The various AutCollab peer support initiatives are, of course, attracting autistic participants from all continents and that's wonderful to see and it's wonderful to see how many autistic people are offering their time to help us, for example help us translate important content into languages other than English. I think that's also an important thing to mention that so far, I think a lot of the international conversation amongst autistic people tends to be in English and it's good, but I think we need to encourage more also dialogues in other languages and hopefully translate lived experiences in all directions so that we get greater insights into what's going on in other parts of the world.

In the health care sector we are developing an amazing international network of doctors, nursing professionals and allied health professionals as our true allies and, of course, many of our allies in the sector are neurodivergent, and only few openly identify as such but they can still, I think, help us a lot in terms of getting professional, education based on lived experiences in the right place to the right places. In the coming year, we are aiming to scale up the delivery of these education courses and this will only be possible with the help of these amazing allies.

How do we get international collaboration going across cultural boundaries, different socio-political contexts and so forth? As I mentioned, translation and language I think is important to

get that going and what we also have to recognize is that all these hierarchical social structures that we have basically in all countries stand in the way of collaboration across cultural and organizational boundaries at all levels of scale and this is I think where we can link or to make people understand what drives autistic people and in why we should be listened to in this time.

We can link this to all the existential risks that humans are facing right now, right? I mean the cultural inertia of industrialized civilization will either lead to the extinction of the human species or somehow humans will rediscover an interest in genuine collaboration without any hidden agendas and to do this primarily at the small scale – at the human scale that’s comprehensible, because that’s where we can collaborate based on mutual trust. And if we can then also rediscover ways of collaboration between such small groups, well that could be the emergence of ways of even cultural revolution that are not dictated by social power gradients and deep hierarchies.

[49:55]

And it’s in this latter scenario, this optimistic scenario that humans will find a way back to more collaborative ways of being that I think autists are uniquely equipped to act as catalysts and as translators between different cultures and groups because (a.) Autistic people have to spend much more conscious effort in understanding each individual, so if we have a conversation, we take our time and we make sure we actually understand. We don’t simply absorb opinions from other people. We always have a critical lens, even our own culture. And then secondly, we tend to be trustworthy, because I think at least that’s my experience we are more-or-less unable to maintain hidden agendas over long periods of time in which is the essence of what you have to do in order to be successful in, you know, our industrialized societies that are based on the industrial models of success.

Just to re-iterate this sometimes, I get this caveat from people, but ya, hang on, autistic people, sure we also lie and so forth. Yes, autistic people are *capable of lying* but the point here is maintaining hidden agendas, this is something different from lying that we sometimes have to do to basically survive...that’s my experience. I don’t know whether you have opinions on this but that seems to resonate well with most of the people that I engage with.

Now, just to continue here, autistic people tend not to be as deeply embedded in the locally dominant culture as neuro-normative people and this also makes it easier not only to relate to other autistic people but also to those from very different cultural backgrounds. And, in abstract terms, how do I see mainstream culture evolving or human cultures evolving? A few concepts here – I think human organizations or intuitions are best thought of as cultural organisms, and groups of organizations with compatible operating models can be thought of as

a cultural species; and if we do this then the human genus really is the genus that includes all these different cultural species, and with these maybe somewhat abstract concepts we can now understand that this NeurodiVenture concept and that we can experimentally sort of developed and have been successfully operating now for ten years – that’s a concrete example of an emerging, global, cultural species that provides safe and nurturing environments for divergent thinking, creative exploration and collaborative niche construction, as I said earlier, and so this idea of neurodivergent collaboration I think is a deep topic.

It’s very close to my heart and it’s covered in greater depth alongside other topics in my book on *The Beauty of Collaboration at Human Scale*, and the subtitle of that book is *Timeless Patterns of Human Limitations*; and every word in the title of that book including the subtitle has been very carefully chosen, but you know words have limits. So what really what I’m trying to convey in this title is that life feels like a dancer trying to balance all these words and concepts...I think when we engage in the collaboration at human scale at this small scale only with people we actually know and trust – where there’s a mutual trust and we can operate based on this trust, not based on power gradients and so-called *authorities*, then we are nourishing our autistic whānau. We are able to nourish and create chosen autistic extended families.

Ultimately, I think we are feeling well and healthy if all these relationships in our whānau are providing us with the right kind of nourishment for everyone, right? This has nothing to do with the competitive economic paradigm that we currently have to live in.

**Anne:** I think that the piece that I see coming out of all of this, also is imagination – that autistic imagination, within autistic culture is one of the things that’s going to help us get out of the disaster that we’re in right now as a world. And projects like yours are some of the most important work that’s being done, not only to help neurodivergent people have better quality of life, but also to improve the quality of life on the planet. I’m just so happy to have you on the show and hear about your project, and I was hoping that you could share your website and your social media and other places where people can learn more about AutCollab.

**Jorn:** yes, absolutely. There’s the AutCollab website, [autcollab.org](http://autcollab.org) and what you just mentioned really is a super nice way of wrapping up. If you ask me what’s the biggest crisis that we are facing I see two inter-connected crises. One is the crisis of a lack of imagination and this has directly to do with the oppression of autistic and otherwise neurodivergent people and this crisis is deeply connected to the crisis of institutions that I think everyone is familiar with, right? Far beyond the autistic community.

We all, I think everyone today recognizes that somehow we’ve ended up with ossified institutions that are not only dysfunctional but also incapable of changing, right? And we need

to imagine not only new ways of living and working together, but to imagine a world where the current institutions that we have, where those types of institutions are no longer relevant. Where they've become obsolete. And that's going to be a good thing.

**Anne:** Thank you so much for being on the show and we hope to learn more and have another conversation with you as well to continue along with some of these thoughts...because there's a lot to unpack. Thank you again so much for being on the show.

**Jorn:** Yeah, thank you so much as well. I mean you've asked big questions and I think those questions deserve proper answers and while those answers can't be covered in one conversation I think we should also try and weave further people and further autistic wisdom from all over the world into this conversation.

**Anne:** Definitely. Thank you.

**Jorn:** Thank you. Take care.

**Anne:** We were just speaking with Jorn Bettin. He spoke to us from Aotearoa New Zealand.

[Outro music: Jazzy synth pop music]

**Anne:** You're listening to Noncompliant, a neurodiversity podcast. I'm your host Anne Borden King. Noncompliant is recorded at MCS studios and transcribed by Julie-Ann Lee. This episode was engineered by Lucien Lozon. Thanks to our team and thanks for listening.