

From the Old Brewery S1-EP3

Speaker 1 [00:00:03] This podcast is brought to you by the University of Aberdeen.

Suk-Jun Kim [00:00:22] Hello, I'm Dr. Suk-Jun Kim, I'm the director of the postgraduate research at LLMVC.

Ian Grosz [00:00:28] Hi, my name's Ian Grosz. I'm a Ph.D. research student in creative writing, and I'm co-hosting From the Old Brewery Podcast along with Jun.

Suk-Jun Kim [00:00:34] This is our third episode and we are actually for the first time. We are meeting together, so it's very nice to talk to you in person, you know, rather than relying on technology and talking through the various topics that online. And this episode we have Sarinah O'Donoghue, who is a second year Ph.D. researcher, and her research is about exploring narrative representations of autism. She graduated from the University of Aberdeen with their first class honours in English literature in 2020, and later that year she began her Ph.D. with a submissions from Professor Timothy Baker and Dr. Jacqueline Ravet. So her passion for championing neurodiversity led her to co-found at the narratives of a new diversity network, which is a vibrant online community of neurodiverse, divergent led academics and creatives, which was founded in July 2020. She also has been creating and producing videos on autism acceptance for the BBC social channel since June 2019. Welcome, Sarinah.

Ian Grosz [00:01:48] Hello. Hi, Sarinah. You're obviously heavily involved in championing and exploring issues around neuro diversity, personally and in your academic experience, and just wondered what brought you to this, this deep interest you have in neurodiversity and autism specifically?

Sarinah O'Donoghue [00:02:05] Um, I guess I wanted to find a way to bring together my two passions. So, you know, on the one hand, there's neurodiversity and championing that. And then on the other, there's literature, and it got me thinking that, you know, what's happening with autism and literature in, em, contemporary novels and other forms of literature that are being published now. And I came to realise that, in literature, disability studies itself is thriving, but there seems to be a focus on physical disability and on the body. It's almost that disability studies is like synonymous with the body. So I thought, you know, I looked deeper into it and thought there must be some kind of gap that I could address. And then I realised the more into my reading that society – their perceptions are formed on the fiction that's published rather than the medical stuff. So I thought, well, this deserves attention: if you think of *Rainman* [the film] or *The Curious Incident of the Dog in the Night-Time* [the novel], those two are what disability studies scholar Stuart Murray calls 'autism events.' You know, they were that big. So I thought, you know, representation is important. How is it changing? How quickly is it changing? And you know, why has it not got the attention that it deserves in scholarship? So yeah.

Ian Grosz [00:03:39] So the gap in scholarship, and public attitudes are totally shaped really by the literature and the films and the other art forms that are put out there. Can you expand a bit on the links between the representation and what you call the environmental aspects of literature, in your study? Have you got a few examples of that you can give us?

Sarinah O'Donoghue [00:03:59] Yeah, erm, the way that I deal with environment is kind of in the widest sense of the word. So, every angle you look at it, there's kind of some interesting connection. So if you take it on the most general level, erm, in the UK

especially (and in the US) there's this focus in scholarship on what we call the 'social model' of disability, which is the idea that, you know, the lack of accommodation in societal institutions and mechanisms are responsible for a lot of the disablement that happens. Not to say that, you know, people don't have their own sort of struggles within themselves, but that society plays a huge part in the quality of people's lives. So environment is actually, you know, the whole idea of environment underlies the social model and informs how disability is conceptualised and managed and everything else.

Ian Grosz [00:05:07] I can see that, but I just wondered how you linked that with the study of the literature that you are researching as part of your PhD? Is it the way the experience of autism and Neurodiversity is framed by environments in the literature, or is it something else?

Sarinah O'Donoghue [00:05:25] And so, yeah, there is that and the reason I bring that up first is because the other stuff gets really kind of niche and really complicated. At the moment I'm looking at posthumanism and autism, and I'm looking at it in terms of relationality. So this is where it becomes obvious that environment is very kind of broad in my conception, and this idea that autistic people are kind of imprisoned, you know, [ideas of] self-imprisonment and solipsism and things like that, and they don't kind of like relating when actually it's a different form of relation, sometimes it's hyper-relation. So I look at kind of first-hand accounts by autistic people, you know, for example, the description of synesthesia and how that translates in their poetry is inherently relational. And so I kind of like to think about that and to make that point because it's not it's not common knowledge.

Ian Grosz [00:06:29] Sorry, so the environment then encompasses human interaction – the human environment – not just the physical environment?

Sarinah O'Donoghue [00:06:38] Yeah, yeah. So I guess it's this idea of, you know, we are always products of our environments. We're always kind of affected and affecting what goes on around us, human and non-human, but going back to the early kind of easier conception is the way that I've organised my chapters of my thesis. And so the first chapter is the body, and it looks at those kinds of things. You know, how bodies are in space and how they transform space and how they are transformed by space. And the second is the home. So autism is often framed as a family crisis ever since de-institutionalisation happened in the 1960s, and parents kind of found themselves living with their autistic children for the first time, and having to find ways to manage it, and to help their children, and to help themselves. And this is where kind of the most common charities, including the National Autistic Society in the UK, was set up by parents. So autism is always seen as a domestic kind of affair. And that's often framed in tragic terms. And a lot of the narratives I look at kind of challenge that.

Ian Grosz [00:07:55] It comes from the parents, or the family experience, rather than from the individual with the autism or the neurodiversity themselves.

Sarinah O'Donoghue [00:08:06] So in disability studies, we have this term called narrative prosthesis, and it's the idea that disabled people exist as kind of plot devices for exploring, for example, the breakdown of a marriage. Or you know what it's like to parent somebody who's quote unquote different instead of actually looking at giving the autistic character agency: they [autistic people] are often at the centre of the narrative, but have absolutely no agency. So it's those kinds of things that are useful to study within the context of the home. And then we've got the community, which I haven't actually done much work on yet. But I do look at maybe a bit more about the social model and kind of

what comes of that. And then there's non-human environments and kind of the natural sort of world, and I look at memoirs in that chapter. There's so many memoirs at the moment being published by autistic people, including kind of Chris Packham, Dara McAnulty and Greta Thunberg, Temple Grandin, Dawn Prince Hughes. There's a lot of these ideas of, you know, animals and non-human environments and interaction. But that's often framed in dehumanising terms. You've got to be careful not to say, 'oh, autistic people find it easier to interact with animals.' So again, it's addressing and challenging those kinds of ideas. And then finally, I've got sort of science fiction, so I don't know if anybody heard of the spectrum 10k.

Ian Grosz [00:09:43] I was reading about that, on one of the co-founders of the narratives of neurodiversity network: David Hartley. He talks about the 10k, the spectrum 10k people? It's really disturbing; troubling sounding. Can you tell us a bit more about that?

Sarinah O'Donoghue [00:10:02] So, yeah, I actually read very little into as an active resistance almost, and as self-care. But from what I understand is, er, Simon Baron-Cohen, which was the guy who came up with 'Theory of Mind' which suggests that autistic people lack empathy and he wants, I think, ten thousand samples – DNA samples – from autistic people, and I think that the overall goal is to eliminate the condition. And so you see a lot of this eugenicist sort of talk, or the idea that there are those who think, the biggest worry against eliminating autism isn't the clear ethical issues it poses, but the fact that we might not then get the superhuman autistic, you know, the ones that are kind of seen as the savants, the zero point six percent. And so science fiction's a really kind of fruitful field to look at.

Ian Grosz [00:11:01] It's a prescient genre, isn't it?

Sarinah O'Donoghue [00:11:02] Yeah, exactly. So you have a lot of autistic writers and people writing about autism in sort of the future where it is cured or, you know, those kinds of themes.

Ian Grosz [00:11:14] You can imagine historians looking back if that was to go ahead and that became something that was accepted by society, you can imagine historians looking back and being aghast at what was going on. It's incredible, really.

Suk-Jun Kim [00:11:29] Yeah, yeah. I think that too. I was wondering, you know, in your research on the autism, there is a very personal topic in the literature. I guess you started your research and combined these two ideas together and then found some aspects of how autism is represented in literature. So when you were thinking about it, perhaps, one or two, uh, the pieces in the literature, you recognised, oh, there is an issue there. Can you give us some example of a one or two, hopefully widely well-known literature that got you started? Is there anything you can talk about?

Sarinah O'Donoghue [00:12:19] And so I think the less sort of progressive (to put it lightly) examples, they still kind of come quite commonly like recently, we have Sia's short film called *Music*, and there was a huge kind of upheaval about that. And that was only a few months ago. Where, you know, there was a neurotypical actress playing an autistic character. And, you know, they hadn't consulted with any of the, um, with any autistic people themselves. They used a charity that most autistic people oppose because they are for cutting autism, and it was all just very kind of not exactly presented in a way that more autistic people would kind of agree with. And I'm saying this from the discourses I've read. And I guess like, there's the ones that aren't harmful in themselves, like the most

common, *The Curious Incident of the Dog in the Night-Time* by Mark Haddon. It's not that that in itself is offensive, but what happens is a very kind of particularised view of autism is promoted at the expense of all other autism narratives. And so there's a popular saying in the autism community, which is if you've met an autistic person, you've met one autistic person, you know, and that kind of doesn't come across so much when a really popular narrative gets published and it kind of excludes all the other ones, new ones. But having said that, since around two thousand and eighteen and I mean, this is kind of where I pinpoint it, and I am just seeing book after book after book published that are just extremely, kind of, autism isn't even the main thing about it. A lot of them are written by women. A lot of them are written, kind of, you know, that they're very kind of they're interesting, but they're not interesting because they include autism. That's not the main point of them. And so like I'm thinking just recently, there's Helen Hoang, there's Michelle Galen, there's Katya Balen, there's, who else, Madeline Ryan, you know, these publications are coming faster than I can read them, and it's just absolutely wonderful. So there is such a sea change and that has to be accounted for. So that's kind what I hope I'm doing.

Suk-Jun Kim [00:14:57] I do think that is the case as to why there is a certain sudden surge. If you were like, you know, the new or maybe a renewed understanding or maybe renewed representation of autism, perhaps, by the people who have autistic elements in their life?

Sarinah O'Donoghue [00:15:15] Yeah, I like to think that society itself is becoming more progressive, people whose narratives have been silenced up until now, are kind of coming forward and telling their stories, and I think part of it is a wider kind of culture of that know you see on the TV and in adverts, you know, and more and more representation like I think, on my social media pages, I think it's maybe not Google, but it's something similar where, you know, there's a kid with Down syndrome and she's just with her mom. And you know, that's just happened. And then there's the Changing Faces campaign after the James Bond film came out which did kind of their own advert, and it was people with kind of visible facial differences not acting as villains. But, you know, posing as the protagonists.

Ian Grosz [00:16:08] Yeah, that's really obvious in the Bond franchise, isn't it? The disfigured villain.

Sarinah O'Donoghue [00:16:13] Exactly, yeah. So I think it's happening in in lots of different kind of areas of disability studies and further afield. And I think in autism specifically (I'll probably get to this later) but the internet was kind of the main place where autistic people have always gathered, have always mobilised. And so if you think about it in kind of in historical terms, it wasn't that long ago, you know, the first autistic-led Listserv was in the nineteen nineties, late 90s or early 90s. And so it does take a long time for things to change, and that was the seeds of it. And I like to think now, sort of 30 years on, we're really, really getting into it now, it's gaining momentum in other areas of publications and culture and things like that. Having said that, the internet still remains kind of the main place for autistic people to gather and publish their narratives kind of unofficially and things like that.

Suk-Jun Kim [00:17:17] It got me curious how you explain to us about your trip to plan how that first chapter has to do with body and follows on with home and community. And uh, this idea of the post-human, where you particularly focussed on their memoirs? And then that leads to sci fi. So, I felt like, the sci fi element: on the one hand, you know, of

course, it may have to do with the post human on the one hand, but seems like a kind of a bit of a jump. And also, the sci fi element seems to be kind of put in the latter part of your dissertation as it currently stands. I wonder why this kind of structure? Do you see that Sci-fi is one of the genres where maybe there is a possibility of a rewrite or renewed representation of the existing representation of neurodiversity in a freer form? What do you see there, the possibilities in sci fi?

Sarinah O'Donoghue [00:18:32] Yeah, I think sci fi is the most kind of 'out there' of the subject areas that I'm focussing on within neurodiversity. I think that it's maybe a good way to tie in what the previous stuff in the thesis looks at. Because especially with the posthumanist stuff at the beginning, it would be nice to kind of return to that in the sci fi thing because with posthumanism, a lot of people just see it as not in the body, but you know, the mind being kind of a computer or something to process. Well, there's interesting parallels between that, and in sci fi (and often not in sci fi) autistic people are often equated with computers and processing machines. This kind of idea that they're unfeeling and they're just good at numbers and nothing else.

Suk-Jun Kim [00:19:36] Somehow this reminds me of Data in Star Trek. You know, some quality seems to be, you know, if he were a human being, maybe some quality of the character maybe is considered autistic in a way, isn't it? You know, that's a very interesting one.

Sarinah O'Donoghue [00:19:55] Yeah. So it's so yeah. I mean, like, I haven't actually started the sci fi stuff yet, but what I call it in my chapter and in all my proposals and stuff is the idea of imagined spaces, you know, so if you've got physical spaces that you know, people frequent day to day like the home or like, you know, natural environments, the imagined spaces does kind of take these ideas to the very furthest they can go. And I feel like with sci fi, there's a lot of kind of reductive representations of, you know, for example, the autist as automaton, which, um, which is

Ian Grosz [00:20:36] Are there any...I've read a little bit of sci fi and I love sci fi films, and I just wondered if there were any actual representations of autistic people in sci fi or whether it's just the way society reads into some of the traits that some characters in sci fi might have, you know, AI robots and things like that.

Sarinah O'Donoghue [00:20:56] There are definitely. I know. So I like sci fi. I'm not kind of a sci fi buff yet. I have a while to go and I will be reading my sci fi. But I know that a lot of characters that we're sort of are not explicitly written as autistic have been read as autistic in sci fi and like Dave, Dave Hartley, who is one of the co-founders of the NNN. He did his thesis on representations of autism, and he looked at *Bladerunner* so he would be a good one to ask, actually.

Suk-Jun Kim [00:21:37] And yeah, actually, I thought about Blade Runner. Yeah. Yes.

Sarinah O'Donoghue [00:21:40] Yeah. So. So there is that. But there's also there are named representations of autism as well, like Daniel Keyes *Flowers for Algernon*. And also, we've got the Elizabeth Moon *Speed of Dark*, where a cure for autism is actually available. And that's been read kind of in two ways. I'm not big on it. And then there's other sci fi authors who are autistic, and they have explicitly sort of expressed their love for sci fi as being a place where they can actually kind of explore alternative possibilities and societies that are more accepting. So the two that come to mind are Rivers Solomon and Dora Raymaker. But yeah, so autism in sci fi, there is a lot there. It is the kind of part of my

chapter because it's last, what I've thought least about, I will say, but I know that there is a lot to be discovered there and I'm very excited to get into it.

Ian Grosz [00:22:47] Do you think it will tie up a lot of those other aspects that Jun touched on: the home and the body and the family?

Suk-Jun Kim [00:22:55] I was just thinking about this. So why sci fi, you know, uh, as your current research stands, why you placed it to the last chapter, and I thought that maybe in sci fi, as you mentioned about imagined space, you can imagine different environments and you talked about why environment is really important in this representation of the autistic experience. And if you are kind of positioning, of course, you can imagine space in whichever era you always have to imagine. But then if you were to imagine us at a certain place like a 20th century or 21st century, the current one or even going back to like 18th or seventeenth century, you are limited by the human structure or, you know, you know, conceptions about the environments that you have to navigate through it. In Sci fi? Yes. You still have to. But then there are a lot more freedom in terms of however, you can imagine the environment. So that may have something to do with it.

Sarinah O'Donoghue [00:24:02] Yeah, definitely. And I think like as an aside, when you were talking about earlier eras, it's hard to talk about earlier literature when diagnoses didn't exist, like, I'm not a psychiatrist, I'm not somebody who's qualified to say whether certain people are autistic, aren't autistic, who are no longer here or who are here for that matter. And a lot of people feel the same. There's there's mixed opinions, but I feel like with sci fi, then you can. It's kind of easier to imagine the future. It might even be the way that diagnosis is done. It might even be that diagnosis isn't needed anymore, you know?

Ian Grosz [00:24:41] But Societies adapted to people with autism, rather than people with autism having to adapt to the society.

Sarinah O'Donoghue [00:24:48] So it's just such fruitful ground, and I can see why, you know, authors would take that as their setting.

Ian Grosz [00:24:55] Before we go into the narratives of neurodiversity network, to talk about that, I just wanted to come back to your discussion about environments and social environments, and how you felt that relates to your own experience in the university environment, and how universities approach it today, in comparison to the past, perhaps?

Sarinah O'Donoghue [00:25:15] Yeah. So I guess like most people doing a Ph.D. myself included, think about not just the academic side of things, but the practice. You know, even those of us that don't end up staying in academia might well do some teaching and interact with students and other members of staff. And so I am interested in kind of not just the theoretical and academic side of things, but how to make, you know, universities and institutions more sort of aware and more accepting of lots of different types of neurological difference. So I've kind of I've seen sort of both the good and the bad side. I was at a previous university where I had to transfer here from my fourth year.

Ian Grosz [00:26:00] And that's a big upheaval, isn't it? At that point in your studies?

Suk-Jun Kim [00:26:05] Yeah. For three years, the final year,

Sarinah O'Donoghue [00:26:08] I was completely unexpected. It was just that the accommodations they wouldn't stick to. I think it was as if they didn't believe I was autistic

or they just, I don't know, but I had to come here. It was very last minute. I'm from here, so that's why I chose here. And (well I didn't choose) but I came here and I remember going into my first class and thinking I will get my head down and I will leave, and that will be it. You know, I'm sick of this environment I'm sick of, you know, the way that they treat anybody who has different methods of learning. So I got there and I did the first class and I was trying not to be, you know, kind of involved and taking part, but I couldn't help it. The person that I met was great. He's now my supervisor and very soon, immediately I began sort of thriving, completely thriving, doing really, really well, not only academically but socially. And I felt like I had a place.

Ian Grosz [00:27:10] Can you tell us what the difference was? What made it a more welcoming or accommodating environment?

Sarinah O'Donoghue [00:27:18] Yeah, so like for the first university it was it was kind of like, I don't know, it seemed to be a culture thing where they didn't really do things that would benefit students generally. If you had some, if you had a special request, they would sometimes do it. And so, for example, for me, it was as easy as simple as getting materials early. So because of my autism, but also because of my other health problems, I like to have the opportunity in the holidays when I was an undergrad to do the reading then. So just the reading lists, for example, is what I would ask for. And they didn't provide the reading list for a one course. And then so I put all of my effort into the other course. I got back and I found out that they enrolled me in the wrong course, so I had done none of the work, and they were basically just refusing to give me, you know, any sort of leeway for that, even though I'd done work for the other, of course. So it was just things like that and also just not having quiet spaces in the library, being put in cupboards instead of, you know, designated spaces and things like that. And then when and I had a lot of, you know, notes on my disability services file saying, you know, she must be given this early and, you know, Sarinah must be allowed to get up and, you know, leave if she gets overwhelmed and things like that. And then when I came to Aberdeen, I told my supervisor, I said, you know, 'I'm not registered with the disability service, but these are the issues I have.' And he said no problem. And it turned out that it really wasn't a problem. And so things like he did this scheme where it was like you had three days extension, it was called that the soft deadline. It was like a pilot scheme. And you would have three days if you suffered from any type of kind of mental health issue or disability or just any problem. You wouldn't have to go and make a case for yourself. You would just get those discrete kind of three days another time. I find it very, very difficult to work with other students because of how early I began things, you know, I wouldn't expect anybody to begin that early. I said that to him and instead of him saying, Well, you've got to take up with this person and then you have to go here and write your case down clear. No problem, and we'll come up with something else. And not only did he say that to me. He said it to the whole class. So it's this culture thing, you know?

Ian Grosz [00:29:46] So it's just a flexible approach to teaching and learning.

Sarinah O'Donoghue [00:29:49] and it's often just the smallest

Ian Grosz [00:29:50] And it doesn't single anybody out.

Sarinah O'Donoghue [00:29:52] And that's exactly it. My hope is to kind of nurture an environment where it's not like, Oh, we must be very accommodating for any student that come to us, but instead say, OK, what can we do as a whole department to make sure? Because I think, yeah, sure, autistic students with autism diagnoses are kind of vulnerable

to maybe, you know, not getting sort of the equal treatment and things like that. But it's often the people without the diagnosis that are the worst off or, on top of that, people who don't even know that they might be neurodivergent. Those are the people that we also need to help. And that's the only thing that can be done there is a culture change.

Suk-Jun Kim [00:30:35] Is there anything that you felt that you know, that either you yourself have felt or maybe you identify or recognise that there's something perhaps lacking in Aberdeen, something that you wish that could have been done or even we could have done further or more.

Sarinah O'Donoghue [00:30:53] I mean, I've been very, very lucky here. If it utopian, it's only because I have had very few in-person experiences here, like I did my fourth year here. I only had two members of staff working with me. And then when I went to do COVID that one of those members of staff is now my supervisor. And then the other one, Jacqui Ravet, she's an autism specialist. So I have been very lucky in that I haven't come kind of face to face with any difficulties myself. However, I have heard from other people that you know, that things can be quite difficult in other areas. So, you know, there's one person I heard of and they were saying in their department, there seems to be kind of this disconnect between all the members of staff, and they don't have the same kind of an ethos or approach to issuing work and things like that. They kind of take their own liberties and members of staff said this as well. And so I do recognise that there are problems and I'm lucky enough to have not gone through them myself. But I don't think, you know, I don't think that we will be done for a long time yet.

Suk-Jun Kim [00:32:19] So I think that the fortunate environment to you, you find yourself with your supervisors and your two supervisors. I think that, of course, in one sense, those are kind of personal commitment by themselves. But I think some elements could be implemented from top down so that, you know, as you just mentioned, maybe some other people or students are struggling because, not the exact environment that you were in, you know, you were enjoying, but similar elements could be implemented as a policy from top down so more or less, you know, there are other occasions where some departments or some schools are doing really well, but others are not doing so well? So that may mean that it's got to be, it's got to have some kind of a core school discussion or even higher up..

Ian Grosz [00:33:16] This could be central to university policy – a holistic approach.

Suk-Jun Kim [00:33:19] Exactly right. So some good, you know, good practice being shared between departments within schools so that there could be measured and then implemented as a policy.

Sarinah O'Donoghue [00:33:32] Yeah. And that, I mean, I'm well aware that that's kind of not happening. I mean, there's recently kind of new approach to deadlines that are very strict and very rigid. And, you know, there's sort of, you know, just kind of practises that like even just the no detriment, for example. I'm not saying that I have a, you know, a serious stance in that I wasn't kind of involved in it. But I looked at the students and I thought, you know, if that was me in my worst time at university, that would have finished me, you know? But in Aberdeen, when I was doing well in my fourth year, I would have coped. But in other times, you know? So I do look and I do feel like there are a lot of these policies that come from high up. And they kind of affect the students who are struggling the most. And, you know, you should never assume that it's because of laziness or it's their fault, their own fault and things like that. You know, it's just

Ian Grosz [00:34:34] It's just because the whole thing is set up on a traditional model of education, isn't it?

Suk-Jun Kim [00:34:40] You know that this is really important and we need to talk about this more openly. You know, as we all know that this is right now a transitional time. And for the last 18 months or even almost two years long, the university had implemented this temporary detrimental policies and along with it, other kind of measures implemented as a kind of ad hoc. And now we try to recognise that these elements are temporary. So we are trying to kind of clock back and going back to so-called normal, but we all know that there is no normal right now. We are never going to go back to normal, you know,

Ian Grosz [00:35:27] also some of the things that weren't normal were positive. You know, there were some things that were positive and perhaps, in all areas of life, but the university should look to cherry pick some of the things they implemented and say, well, this was working quite well so we can keep an element of that. But we're getting sidetracked now. But this is maybe something you could look at, like a cross university forum, but you're pretty busy already aren't you, Sarinah. You've got so much on the go.

Suk-Jun Kim [00:35:52] Yeah, about that. While I was listening to your story about how you experienced it from another university and having had some difficulty moving to Aberdeen, Is that about right? Is it 2019, 2018?

Sarinah O'Donoghue [00:36:10] Yeah. So the transfer happened. It became very clear that they didn't plan to help me. And it was a kind of last straw thing, which meant that it was like, I think the university was to begin again in sort of three days' time and we realised now I can't go back there. So I actually ended up having to take the year because I couldn't enrol, you know, immediately. So, yeah, so I left that place in September 2018, and then I came to Aberdeen the term 2019.

Suk-Jun Kim [00:36:53] that's interesting. Or maybe this is co-incidental. But when I was looking at your bio, you started working with the BBC social channel in 2019 and then in 2020 you co-founded this, you know, what's called the neurodiversity network, isn't it?

Sarinah O'Donoghue [00:37:13] Yeah. Narratives of Neurodiversity Network.

Suk-Jun Kim [00:37:15] Yeah, Narratives of Neurodiversity Network.

Sarinah O'Donoghue [00:37:16] It's a bit of a tongue twister, so we usually just call it the NNN.

Suk-Jun Kim [00:37:20] NNN. So it seems like maybe I'm, you know, I'm stretching a little bit, but it seems like you find a place that you feel very comfortable in both your personal life, but also, you know, in your academic life. And then you kind of regain your energy to not only do your own work, but also, OK, how else I can, you know, link up with other people and talking about this more public publicly?

Sarinah O'Donoghue [00:37:47] Yeah, definitely. I think when you've had the kind of hardships that, you know, the discrimination that you go through and the impact that has on your mental health, like for me, certainly the only way in that year off, that I could kind of come to terms with it was to be active about it, to write about it and to kind of spread awareness. Because when I was doing those things, I thought to myself, you know, if one person could understand a bit better, then that really has a huge effect, maybe even not on

the individual, but on somebody that they know and, you know, things spread that way. So I think that between having the year out and coming to terms with what had just happened, you know, I worked really hard to get into that university and I tried to build a life for myself there. And it just I just watched it kind of crumble through no fault of my own. And I thought, I am fortunate to come from a very supportive family and a family who is able to help me and you know, there was a place for me at home, for example, when I moved back. And they also helped with the whole transition. All my siblings and my parents, if I didn't have that, you know, or if you know, if I, if I or even if I came from a family with less support financially, emotionally, I definitely wouldn't have made it. There's no question about it. I wouldn't have transferred. I would have dropped out and become a statistic. And so I thought to myself, I must use not only my hardships, but also my privilege and my, you know, the things that I have. I am fortunate to have to share my narrative to maybe help somebody else. And I mean the reception from the videos for BBC, The Social Example, for example, like I get messages every time a video comes out. You know, there's a few people coming to me and saying, 'You know what? That really changed things for me' or 'I didn't realise' or 'thank you,' and that makes it worth it.

Ian Grosz [00:40:03] Yeah, well, what doesn't break you, makes you, right? Can you tell us a bit more about the videos, what sort of content you put out?

Sarinah O'Donoghue [00:40:11] So, yeah, I mean, before I started the videos, there was a brief kind of stint where I did columns for my previous university magazine. So I got my diagnosis of autism going into my third year because I was

Ian Grosz [00:40:27] So, that late?

Sarinah O'Donoghue [00:40:28] Yeah, I mean, it was brought up to me much earlier, but I got the diagnosis in order to access the provisions and things like that. That obviously backfired. The provisions didn't prove to actually have any kind of weight to them. But after I got my diagnosis, I thought, Right, OK, I'll write. So it was I wrote some columns titled collectively *Neurodiversity at University*, and yeah, I did them. And then I decided that, you know, I would like to do more. So I was watching a video for The Social. And somebody was explaining what it's like to be autistic, it was a wonderful video and really informative. But it kind of showed sort of the conventional sort of presentations that are often associated with guys, so, so women and non-binary people and are kind of underrepresented. So I just I just messaged them and said, 'Hey, that's a great video. But there are other perspectives, too.' And they said, 'Well, why don't you come in and tell us about it?' And I said, 'Sure.' They've been absolutely wonderful and I've met great people through them, and it's led to other opportunities. But yeah, the videos are about just random kind of topics. The same as my columns. I'll kind of choose a topic like I did one on relationships and dating. I did another on the sunflower lanyards, which have kind of been hijacked now from the original purpose, which was to indicate invisible disability, which isn't really their purpose anymore. But I did one on that and I've done one on kind of anxiety when it comes to studying and I've done one on meltdowns (sensory overload). So, yeah, if I've got something that kind of I want to share, I'll just get in touch with them and say, 'Hey, I want, I want to share this,' and they'll say, 'Well, we'll make it happen for you.' So, yeah, it's a great thing.

Ian Grosz [00:42:37] And so do you just talk off the cuff on the video, or do you prepare something?

Sarinah O'Donoghue [00:42:44] And I am somebody who definitely prepares the script and I stick to it, I mean, when...

Suk-Jun Kim [00:42:51] Well, currently, I don't see any script right now...

Sarinah O'Donoghue [00:42:55] I know, I know, God, I would be nervous looking back, listening back. But yeah, so when they got back to me and said after I said about the video, that was good, but it didn't reflect kind of my experience and experiences I've heard from other people. They said, Yeah, come and join us. And I thought, Oh no, 'what have I got myself into' because I had no video experience, no recording experience. But actually, you can do it on your phone. You can use the iMovie app and you can do lots of cutting. And so what I do is I kind of cram into my mind as much as I can remember from the script. I speak it and then I stop the video and then I remember somewhere and then I add them all together.

Ian Grosz [00:43:39] That's great.

Suk-Jun Kim [00:43:41] So this technology is really helping you to kind of, you know, share your thoughts and you know, through this channel. And speaking with technology, I recognise that your network, NNN, or narratives of neurodiversity network. Yes. And it just started in July 2020, which is in the middle of the pandemic. So I assume that this network probably you had to co-found this network through online only, right? So then the majority of the activities until now, I guess still through online. So could you tell us a little bit about the how, how you started working towards the co-founding of the network and what kind of activities do you organise?

Sarinah O'Donoghue [00:44:35] So just as I was beginning my Ph.D, I was lucky. I had contact with my supervisor because I knew him. So we knew very early on that that this is what I plan to do. And he said, 'You know, I was on Twitter and I saw a tweet from Dr. Anna Stenning, who's the one of the co-founders, and she's looking to.

Suk-Jun Kim [00:44:57] Sorry, she is based in..

Sarinah O'Donoghue [00:44:59] She's based in Leeds. So, yeah, so quite a while away and she was looking to set something up. And the first thing my supervisor said was 'it may well come of nothing. These things often, you know, nothing often comes about.' And I said, you know, 'Anna Stenning, Oh God, I've read her work. You know, this is exciting.' So I got in touch with her – when you work in an autism studies, this is one of the exciting things about, it because it's so small, you actually connect with a lot of people who you really admire and respect. Whereas if you were working in, say, Shakespeare, you might never meet your heroes, you know? And so anyway, I got in touch with her and another person called Dr Gareth Farmer. He works in the University of Bedfordshire. I think and we kind of we all got together and we thought, Right, we'll do a Listserv. So we were back to the very first (and this is a neurodiversity network. So it's not just autism, it's all forms of narrative and neurodivergence.) But we were back to kind of the roots of the of the Listserv in the 1990s, and it was all very it was done through Jiscmail. So it looked very 1990s. And then we got kind of some people interested. They we were just what we would do through the list serve as we would discuss kind of book recommendations or, you know, we would discuss experiences in academia or, you know, we've got teachers, we've got students, we've got people who, you know, just have kind of jobs that have nothing to do with new diversity of all types of people. But I think we did a book group kind of meeting, and we decided after that we'll recruit some more people. And so we recruited a few more and we

came up with a Discord channel. It was Dr David Hartley that put us all in discord. He's one of the members now one of the founders now alongside Dr Louise Creechan from Glasgow. David's, Manchester and Louise is in Glasgow. So we're all kind of varied sort of areas in the UK. And we put together the discord, so it's got kind of different channels on it. So some of some of it's for academic discussions and thoughts, others is for creative writing. We've got sort of a social channel, we've got a recommendation so people will post links to like talks and lectures and, you know, author appearances and stuff like that. And it's not so much organised around what we call the salons, which are basically they're not just reading groups, but they're, you know, listening groups. So we might do a podcast or watching group or any type of media, the kind of less conventional, the better. And we'll discuss kind of our piece of reading or watching or listening every, I think it's just like, I don't think we've got exact sort of time through it, but it's like once every two months or so. And then we've also got this newer one, which one of our members came up with is academic discussions. So we also do zooms and talk about theory and ideas, and then we've got a creative writing session. But yeah, it's all online.

Ian Grosz [00:48:17] That's quite cool. Academic symposiums in a way, outwith the academy, if you know what I mean; it's good that it's got life beyond the institutes.

Sarinah O'Donoghue [00:48:27] Yeah. And I think that is one of the few positives that COVID had. I think with COVID, people were beginning to work this way anyway. And as I've mentioned with autistic communities and probably other neurodivergent communities, we've always done stuff online. And then on top of that, like because neurodiversity in disability studies is basically non-existent in literature, there really are. You could probably count on your hands how many people within the academies are working on it. We have all just found each other and we're all working together. And I feel really close to these people, you know, they're my friends. So it's wonderful to have been able to branch out like that and make those connexions and things have come of it, you know, on a understanding had done this amazing festival called the Interdisciplinary Autism Research Festival (the IARF). And I presented it that alongside When was it? Oh, it was in May.

Ian Grosz [00:49:42] Was that an online event?

Sarinah O'Donoghue [00:49:43] yeah, all online. But I mean, the names that were there, you know, so. So there are people that have come up with these pioneering theories that our, you know, our discipline now relies on. They were speaking and then off the back of that, we, you know, I'm now in touch with, for example, one writer called Joanne Limburg, she writes on autism, and she's very well known in that area. She attended one of our salons and we and that and we were reading her book for it, and she came and spoke. And James McGrath, who's a poet and a critic, and he'd come to another one. So it's been just wonderful. Yeah, it's probably one of the highlights of this past year for me, let alone my academic research.

Suk-Jun Kim [00:50:28] How many members do you think that the NNN might currently have?

Sarinah O'Donoghue [00:50:34] So like, actively so this is the people that are posting all the time. It's probably about twenty five very active members, but we've got kind of well over a hundred and from all different areas and again, people. People that we admire as you know, people, they seem very far away from us. Their name will pop up and we'll think, Oh my God, we've made it. So yeah,

Ian Grosz [00:50:57] I can see your face lighting up when you're talking about this. For want of a better expression, because it's a bit of an annoying expression, but you've found your tribe?

Sarinah O'Donoghue [00:51:06] Definitely.

Suk-Jun Kim [00:51:07] So I guess the NNN activities, so there are definitely those activities that will fit well, you know, will be fed back to your own research and how do you see that happening?

Sarinah O'Donoghue [00:51:22] So I think a lot of it is just in the casual sort of day to day. So like if I say if I was up, you know, studying at the moment and I kind of hit a roadblock or something, I would the first thing I would do is I would go to the Discord channel if it was to do with like the autism side of things for us to do with the farm or maybe the wider theories that would, of course, be my supervisor. But if it was the autism stuff, it would be recommendations and I would get I would get recommendations. I would get, you know, probably one or two people saying, you know, do you want to zoom and have a talk about it? So it's been very especially at the beginning when I'm sure. And both of you, having done Ph.Ds, it's very overwhelming at the beginning because, you know, so even if you saw and read everything that there is that's relevant to you, you still wouldn't get through it all because it just keeps coming. So it was really, really useful to have people who were well, they were great role models, really, because they were kind of a bit further along than me. A lot of them had just finished their Ph.Ds or had been working for a year or two after the Ph.D, so I did, I do, kind of see them as like supplementary sort of supervisors. I definitely see them as colleagues. So, yeah,

Ian Grosz [00:52:41] Like a peer support network, because, it's quite difficult to establish that when you start your PhD, especially during COVID.

Suk-Jun Kim [00:52:47] So this network is not only about the people who are doing research on the literature, but anyone can join it.

Sarinah O'Donoghue [00:52:58] Yeah. Anyone. And that can be like, I think it's really exciting when we have undergraduates join, because that indicates to us that people are thinking about it much earlier now, I mean, teaching undergraduates about neurodiversity studies is unheard of. But teaching them about disability studies is normal. It's something that happens. If you ask most graduates in English Lit, most undergrads, they will say, 'Yeah, we've been taught about disability studies.' So it's very exciting. It's often because of my colleagues in Leeds and things like that who have been who have been alerting people to it. But we are getting members who were much earlier on in their academic careers. But we also have non academics and people who, you know, either don't have jobs or who work in jobs that have nothing to do with neurodiversity. We have people who are interested in creative writing, but maybe not necessarily the academic side of things. We have people who just want to join in with the social stuff and contribute every once in a while. And we do like the idea that we do like to think that we're kind of non-hierarchical and collaborative. And if somebody's got an idea, they don't really need to come to us and say, 'Could you make this happen for us?' We would say, 'that sounds great, do it. Would you like any help?' And so, yeah, it's it's just I do like the kind of multiple sort of functions of it. And I think that that that's possible now that we've got a few sort of sort of founding members.

Ian Grosz [00:54:39] Yeah, I was just going to ask where, for our listeners, where we can check out the network, the narratives of neurodiversity network, if they want to investigate that and also where exactly we can find your videos on the BBC social channel, if you can, and we'll post a link. So perhaps if you can just mention it just now, that'd be great.

Sarinah O'Donoghue [00:55:01] So I mean, it would be more helpful if either my first or second name were easy to spell.

Ian Grosz [00:55:07] Easier than mine. I'd say.

Sarinah O'Donoghue [00:55:09] why is my name, not just John Smith is, but if you Google my name, Sarinah O'Donoghue and just BBC the Social, it'll come up. And with the Narratives of Neurodiversity Network, the easiest way to do that is to find the Twitter handle, I think it's 'neuronarratives.' And then the link in our bio, there's a Discord channel. But even if you're not keen for signing up on Discord and getting involved with kind of the sort of discussions on there and you just want to come to the meetings and stuff, you can just find all of the updates and things on Twitter. So yeah, it's we try to kind of keep the calendar updated on there as well.

Ian Grosz [00:55:53] So it's Twitter and the handle is, again?

Sarinah O'Donoghue [00:55:55] neuronarratives,

Ian Grosz [00:55:56] Great. And then just Google your name: Sarah O'Donohue and BBC social networks.

Suk-Jun Kim [00:56:03] So one last question. So what's your hope? What's your ultimate hope for your research of during your PhD?

Sarinah O'Donoghue [00:56:12] I just hope that I can continue making the connections that I've made. Maybe meet some of the people that I've met online in person and do some sort of reunion. Is that what you would even call it? I don't know in COVID times. For my research: I just hope that it will have an impact that it will matter. And even if even if it inspires one or two undergraduate students, say, to find the thesis somehow and say, you know what, this needs to happen and in our department, we need to start focussing on cognitive difference and we need to start. Or even if I could change something on the more practical level. I know that my supervisor does keep me up to date, Tim tells me that, you know, and some of the things that I'm doing and some of the things that I've raised, you know, he will bring up issues for, for, for neurodiversity in universities and stuff. So I feel like it's an attainable goal. And if I just keep trying my best and if I keep, you know, just keep being passionate and keep working hard, then I'll get to inspire as many people as possible.

Suk-Jun Kim [00:57:35] Thanks, Sarinah. So this is Sarinah O'Donohue, and we had a really interesting discussion. Thanks so much. And thanks, Ian.

Ian Grosz [00:57:43] Thank you. Thanks, Serena. It's been really interesting to hear all your work and your research, and everything else you've been doing!

Sarinah O'Donoghue [00:57:50] Thank you. Bye bye.

Speaker 1 [00:58:16] This podcast is brought to you by the University of Aberdeen.