**Conversations in Social Justice:**



**Participatory research with autistic people**

**Podcast transcript**

Series 3. Episode 2.

*In this conversation, Dr Brett Heasman (Psychology, YSJ), Carl Cameron (a lead peer mentor at the autism charity Matthew’s Hub), and Sammy Williams (YSJ researcher and member of Matthew’s Hub) discuss how to do participatory research with autistic people. They discuss various definitions of autism, the historical problems arising when autistic voices have not been included, and how such challenges should be addressed.*

**Brett Heasman**

Hello, everyone. Welcome. I'm Dr. Brett Heasman. I'm a senior lecturer in Psychology at York St. John University and I'm very happy to present to you this month's podcast in conversations in social justice brought to you by the Institute for Social Justice at York St. John University. So today's topic is going to be about participatory research, particularly in the context of autism research. And this builds on research that I'm currently doing at the moment. working with a charity called Matthew's Hub, which is based in Hull, East Yorkshire. And I'm delighted to say that I'm joined by both Carl Cameron who's from Matthew's Hub, and also Sammy Williams, who is currently working on the project and has completed a master's in research with myself and Dr Lorna Hamilton, and is also a member of Matthew's Hub. So we've got some fantastic expertise here to talk about this very critical and Hhot topic going on in research at the moment. So I thought I would just hand over and let them introduce themselves. And perhaps you might like to also add one interesting things about yourself as well. So Carl, would you like to go first?

**Carl Cameron**

My name's Carl Cameron, I've worked in the field of autism for around 25 years, both in this country and in the Republic of Ireland. I received an autism diagnosis around seven years ago, I was diagnosed as ADHD about four years ago, and I have a master's degree in autism. And I am a qualified teacher. I taught health and social care at a college in Lincoln for a number of years, and I currently teach on part of the Social Work Programme at the University of Hull within Matthew’s Hub I'm the Lead peer mentor on responsible for a training and development which involves putting on workshops across the city and the East Riding of Yorkshire. At least one interesting thing about me? Yea “jag pratar lite Svenska”. I speak a little bit of Swedish. I drive everybody mad with it. But I need to be able to practice somewhere and unfortunately I practice on my family. So they're picking it up slowly.

**Brett Heasman**

Brilliant, thanks, Carl, really impressive to hear as well. Why did you learn Swedish? Was there a particular motivation?

**Carl Cameron**

I've always wanted to learn another language. And I had a year that I have to take off because I had financial difficulties paying for my master's degree. So in the middle I had to take a year off, and nothing to do for a year, so I learned Swedish, well that’s how it started, I've been speaking about five years now.

**Brett Heasman**

Oh, wow. That's incredible. Yeah. Excellent. Okay. Sammy, would you like to introduce yourself?

**Sammy Williams**

Yeah. I'm Sammy Williams. I'm an assistant on the Sandbox project with Brett. And I've recently finished my master's degree at York St. John with Brett, I did a master's in with the experiences of adults with autism as well. I'm also a member of Matthew's Hub. I live in the area and I'm also autistic myself. So I attend Matthew's Hub. I'm about to be in an opera. Well, it opens next week in The Pirates of Penzance. It's the first dress rehearsal tomorrow, I'll be playing a pirate.

**Brett Heasman**

Excellent. Okay. And then myself, I guess I should do something interesting about myself. I have been learning how to build a stone wall recently, which is way more complicated than you think. A lot more engineering going on. I bought some reclaimed stone from the farmer that lives opposite me all completely different sizes, which has made my task much more harder than it should have been. And what I thought would take a couple of weekends is taking months. It's yeah, hard work, but fun!

**Carl Cameron**

Yes I’m from the Peak District originally, so I know what a good dry stone wall looks like , they are a joy to behold aren’t they?

**Brett Heasman**

They are yeah. And there's a high degree of pride because there's only one street in my village and there's a cafe opposite. So everyone passes. At the Jubilee celebration last week, when I was introducing myself to other villages. They're like, “Oh, you're the you're the stone wall guy”. I’ve been building it for ages. So I'm now notorious. So yeah, a lot of pressure my first wall, and it's very visible to the village.

**Brett Heasman**

Our project at the moment that we are running at York St. John, and it's a multi expertise project. So it's with Matthew's Hub, is called Research Sandbox. And the idea of this is that a sandbox, or those of you that don’t know, in programming circles, is a kind of safe space for you to test and explore ideas. And we really liked that concept in the context of doing research. And one of the reasons the motivation came about for developing this project of research Sandbox and thinking about what research could look like if we were to co design it with autistic people is that there is a longer history of research not being aligned to autistic priorities, and also potential types of harm that can develop when you don't include the voice of the communities that you research. So that's some of the background for what initially motivated us to do this. But of course, it's always good to take a step back and think about some of our basic understandings first. And so first of all, first topic for today is what is autism and how has our understanding changed about it? So Carl, I'll go over to you for this one to start with.

**Carl Cameron**

Autism is a neurological difference. It's present from birth. Autism isn't something that occurs post utero. It presents - while we talk about heterogeneity in autism, that autistic people are very different from each other. In some ways, we're perhaps more different from each other than we are from non-autistic people. Everybody kind of wants a nice clean version of what autism is and want to be able to put it in a box. And it's very convenient to be able to build up that way but it prevents presents very differently in different people. And also autism isn't something that's fixed, it's something that changes over time. So something that might be different or difficult for somebody else earlier in their life might not be so difficult later on vice versa, along with the what we think of the core features of autism, which is differences in social communication and social interaction, and also what we used to call social imagination that insistence on sameness, or a dislike of change, or a preference for routine and infrastructure. We also think about the sensory differences in autism. So for those people who wont be able to see my face on this podcast, I wear a dark glasses. Most of the time, well, in fact all the time when I'm not wearing a really dark pair. When I go outside the proper full pair of sunglasses, I don't wear them because I think they maybe look cooler, I've got often for Stevie Wonder. I just really can't cope with bright lights at all. I've also got difficulties being able to filter sound out. So if I'm in a busy environment, like a cafe, not only can I hear the person speak opposite me, but I can hear everybody's speak, I can hear the cars outside, I can hear the coffee machine going I can hear all the chairs squeaking, I can hear knives and forks rattling around on plates. And I hear all this all at the same time. And I've real difficulty being able to filter out all this background noise and concentrate on what the person is saying. It's like listening to an untuned television sometimes. It can become quite an overwhelming thing. And it's an experience which is common for lots of autistic people. I think when we have difficulty with one aspect of our autism, it appears to sort of magnify everything else among we're all able to be able to manage that because of the environment which we find ourselves in will dictate our life chances or perhaps over being able to cope one particular day. The environments are really important thing and how that's kind of managed as a big impact on autistic people, how we work, how we learn, and generally just kind of kind of the quality of our lives. I guess that would be my sort of initial sort of introduction of volunteer to tell people about the core features what I thought was important and sort of like a, sound bite, that's what I will be talking about.

**Brett Heasman**

Brilliant. Thanks, Carl. Sammy, did you want to add anything to that?

**Sammy Williams**

I don't think so. I think I suppose the main difference that I had difficulty with people not understanding is the differences in executive function with autistic people, obviously. And what does it mean? So it's to do with cognitive ability, which regulates a lot of things like switching tasks, beginning tasks, being able to deal with multiple tasks at once, that kind of thing. So it means that beginning a task even like, you know, doing laundry or something can be immensely difficult, even though nothing involved in the task is in any way difficult or beyond a person's capabilities. It can make things like regulating, like how you switch between tasks, how you prioritise things, very difficult. And it means I know myself, it means when there's more than one thing to do that can get very stressful, things like that will build up and even if all of the things are eminently doable, and don't actually pose any kinds of problem. And I think I know people will sometimes sometimes have a vague idea of difficulties in things like executive function and understanding. But we'll often kind of not assume that that is because I come across as I don't have any intellectual disabilities, and in the likes, I'll come across as what people will describe as high functioning. Now, that's not a very, very good label. It's not what people really should be using, but it's how people in the layman's term would describe me, they don't assume that I will have difficulties with things like that. And then when they find that out, it kind of - I can often worry, it changes how people will think about me and that kind of thing. Whereas if people had a better understanding that it is just encapsulates a difficulty I have, and, and lots of autistic people have, and that it doesn't actually impact other areas of my functioning, you know, it's, it is something I find that people don't tend to know much about, unless they've got experience with from themselves or someone they know.

**Carl Cameron**

Their brains are sort of like, I always think like a bit like sort of like air traffic controllers, air traffic controllers, you've got planes coming in planes coming out, you know, you've got, there's all sorts of priorities that need to be done. There's different weights of importance attached to all these things. So there's not going to be a terrible plane crash somewhere. Deep in our subconscious, we started to do all that executive functioning and even before we woke up know what day is today? what are what do I have to do? What do I need to sort of prepare and to sort of triage you know. To be able to executive function effectively there’s three things individually, we need to be able to do. You need a working memory, you got to be able to remember what it is you were doing, you know, what order you need to kind of do doing things and all that sort of, you know, not not the same as a rote memory autistic people are traditionally very good at that. You need to inhibitory control, you need to be able to stop doing what you're doing and be able to move on to something else, you know, mental flexibility, you need to be able to adapt to change every hour which autistic people traditionally don't excel at. Do you know, and plus which you could be geting really absorbed in something, you know, we all have our interests, you know, it can become more of absorbing.

**Sammy Williams**

Yeah, it's very difficult to switch away from,

**Carl Cameron**

yeah, it is and things that you need to do don’t kind of like get done. We are the marmite people younger, we are either, completely, utterly into something, totally invested in it, or can't be bothered, we're no grey areas, nothing in between.

**Brett Heasman**

excellent. Thank you. Thank you both for providing those perspectives. And I guess in terms of the background of you know, how understanding of autism has changed over time, there's a really good article by Bonnie Evans, which talks about where the term came from originally sort of being coined in I think, 1911, it was to describe a type of schizophrenia, because children were observed as being really lost in their own imaginative worlds. But it's gone through many different transformations in meaning as it's been used by different disciplines that have different norms and assumptions about, you know, what the nature of autism is. And so moving into a clinical literature made it much more pathologized. And in terms of the history of how our understanding of autism research has developed, one of the main challenges that we're grappling with today is that you have a very long history of doing research and using what's known as the medical model approach. So the medical model is a model that says there's normal functioning, when you know, something goes wrong, there's a deviation from the norm that requires some kind of intervention or fixing to bring it back. And that works very well for biological, physiological processes. But there's a bit of a grey area when you're talking about the difference, or what's been termed abnormal is actually part of who someone is. It's part of their identity. It's part of their orientation to the world. And so there is an ongoing debate, which we're not going to solve here in this particular podcast, about the fact that there are different perspectives on autism and how to approach it. One of the ways in which we are framed as researchers in the research we're doing at York St. John is the neurodiversity perspective. So that perspective situates autism as part of natural human variation, so instead of saying that there's something wrong or broken or needs fixing, with an individual that we need to intervene and change them, we should focus more on understanding and recognising their specific ways of orientating to the world and thinking about how we can adapt our environments to be more enabling of their individuality. So it's a different orientation and it has an important impact on the way that research is done specifically, the inclusion of autistic voice is really, really important because historically it's not been there. And so it's been possible for some theories. There have been a number of notable theories in recent years which have been quite stigmatising for autistic people to deal with and Sammy was talking there about part of the challenge for autistic people is what you're experiencing can't really be understood from the outside, if you don't have those same differences in cognitive or perceptual experiences, you can't really see that someone else is experiencing the world differently. And managing the stereotypes, the representations of you is a huge social challenge in which you, you're adding on to an already difficult world to navigate for autistic people. So that's the kind of background of where we got to, and why this question of how do we do research with autistic people rather than on autistic people is really, really important. So that sort of brings us to our project, the Sandbox project and what we've been doing. So I thought I'd just talk a little bit about that, and then move on to kind of two really exciting questions, which is, what should or what could autism research look like? And then the bigger question, which is, what would a more enabling society look like for autistic people. So with our Sandbox project, as I said, at the start, we were aiming to create a space that is more participatory. So you might hear this term, participatory research, used a lot in the social sciences. And the idea is that instead of studying people from the outside, so in natural science, you tend to be - the observer is removed from the phenomena that they observe, - within participatory research, it's recognising that there's an opportunity to co-construct knowledge with others, and that if you do so, you'll actually develop more rich and meaningful knowledge about those particular things that you're interested in. So participatory research is a term that is kind of like an umbrella term. So it applies to a broad range of different practices. And within there, you might have something called emancipatory research, which is the idea that we're trying to recognise that there's a power imbalance. And we're trying to remove some of those constraints that are holding back. So the Sandbox project is a really nice opportunity, given my background in autism research. And having done most of my PhD at Matthews Hub, when did I start back in 2013? It was so a while ago, but it was a really good opportunity to bring together different expertise. And I think that is one of the issues that is also being grappled with, whose expertise is being sort of recognised in the process of how we create knowledge. Because yes, there's academic expertise. But obviously, lived experience is a really important part of that process, and also the expertise of other people that may be involved, such as parents, or carers, bringing together all the different forms of expertise and recognising that, I think is part of creating more holistic, balanced knowledge rather than knowledge that might be a little bit biassed towards particular styles of thinking or particular interests. So the Sandbox project has taken an approach for trying to create a space where members of Matthews Hub can critically reflect on what they would like the research relationship to be. And what's really key within that is actually the ability for us as researchers or hybrid researchers to be transformed ourselves. And I think this is one of the key sort of takeaways so far with a project. It's important that when you define what you want to research, it's not sort of closed off to being changed later on. Because it's very often that if you only ever go and find the things you say, you're going to find, then you've not really developed a new knowledge, you've just sort of extended what you already knew. And the idea of participatory research is that to some degree, it's exploratory, you're trying to develop something that wasn't there before. That's sort of the some of the background to the Sandbox project, we've been doing a few different things. The self transformation is actually, if I'm, you know, thinking about one of the other major takeaways is kind of the main point of the project today, our conversations as a team have been really interesting. And in fact, we've changed already directions in a number of different ways. So originally, we had this idea that we would run research-based workshops with members of Matthews hub to help improve their understanding of the research process. And then we'll be able to move towards thinking more critically about different ways in which we could do research, gather data, build those relationships of trust in more creative ways that might appeal to people's interests. That was a initial template for how we might do that, what we'd realised from attending Matthews Hub so we have what an anthropologist might call a period of immersion, where we're attending Matthews Hub regularly every week, that's so that we can be more familiar to members but also so that we can understand more about what their needs and priorities are. So we're not gathering any data in this period of immersion, but we are using it to sort of build those relationships of trust and also reflect on our own aims and objectives. One of the things that emerged very quickly from there was this very large gap that exists between the daily lives of autistic people and the kind of research that's actually been done by research institutions. So even having a conversation about running research-based workshops was already not quite filling that gap because it was assuming that members had (a) an interest in research that they had perhaps some awareness of what the research process might be. But also, it was kind of forgetting the fact that you're asking people to leave their zones of comfort to take part in an activity that they might not otherwise be doing. And the more that we've been doing this period of immersion, the more we recognise that perhaps too often research tries to orchestrate, to these kind of situations to pull participants in to try and gather data. And perhaps there are more opportunities for thinking about how to embed data collection within existing practices. And I think that's particularly true for autistic people that may have extreme discomfort from leaving any kind of comfort zone.

**Carl Cameron**

Yeah, fair, I think that's your just add to that, you know, the, the the social nights that take place on Thursdays and Friday nights at Matthew’s Hub can be as many as 40 autistic people from the age of 18. And up to, I don't know, whatever, 40s, early 50s, I guess, perhaps, for a lot of people, it's been a really big deal, for them to come to that social event like that, they've been on quite a journey to be able to kind of like get there, you know, and there’s people all sorts of different parts of the kind of like journeys, I guess, like, of which Matthew’s Hub is a part. And I think it's, you know, it's really mindful, I think, when researchers are working in those kinds of environments to be sort of like mindful, a lot of people that, you know, just doing kind of almost what they need to kind of like kind of get by in anything else is sort of like, that's one step too far.

**Brett Heasman**

And that, I think leads on to a second really big takeaway from the project, we've recognised the need, well we were doing it anyway. But we've now sort of formally explicitly recognise, there's a need to slow down the research process, particularly for autistic people. Because traditionally, with research, you have a period of time where you have funding, and everything's always been pushed to the maximum in terms of margins, so there tends to be quite intensive recruitment of participants, and then data collection and analysis and moving on, the space for like exploration for self-reflection for truly developing relationships of trust isn't really there, because to do that, you need much more time than is usually allocated. And so we found that part of initially, we were going to do a period of immersion for about six weeks, but then we realised there's no, we should just keep doing it. Because you know, those relationships are, you can't, even in that time period, develop the relationships you need. But also, there's something about sustainability, like we didn't want to be researchers that just sort of come in from the outside gather data, then leave, as often happens, we're much more engaged ithan that

**Carl Cameron**

I think as well that it is difficult for people sort of not to feel like a subject rather than participant of the results of a subject to like, almost like what you described is like a academic hit and run exercise. Do you know, you know, I think that immersion over a greater period, the data gathered is going to be far richer and far more representative with the views of autistic people than you could possibly do in such a short time.

**Brett Heasman**

Absolutely. Yeah. Brilliant. So that's what we've been doing. We've been continually updating, along with that, sort of the third big takeaway was we've we've developed a new methodology for keeping track of where we're changing our ideas, because it became really clear that this this is actually the tool that's missing from a lot of the collaborative projects that are out there is a clear sort of transparency about who comes up with what ideas and where did you get rid of an idea and why and why did you change direction, because that's all part of the process. So often research thinks about outcomes. But actually, it's, it's the process of how we're doing this, that is the most important to document. So we've been developing a new way of mapping all of our dialogue as a research team and sort of highlighting turning points in our ideas. So it's still ongoing. It's an ongoing project. And there's definitely scope for extending it in the future, perhaps in the form of a PhD. But it's Yeah, so it's still ongoing, but it's certainly been already a fascinating exercise in I know, it's, it's really helped to develop my ideas as a researcher, and we're excited to see where it's going to go. But I wanted to ask a question. Now, back to both of you, which is what do you think autism research could or should look like in the future? Okay, so Sammy, shall I go over to you for that question first?

**Sammy Williams**

I mean, I don't know about should for everyone. But I know I'm particularly interested in things like Phenomenological Research, specifically, looking at the experiences of people, which I find is quite relevant with looking at research into autistic people. Because historically, it's been one of the things that has been missing really, from autism research is the voices of autistic people, their experiences, and actually understanding how they felt what people have been through. And so it's something I'd like to continue researching in the future. I know there's a few recent studies now. And hopefully in the future, there will be more just physically asking the Autistic community what their priorities will be. And then perhaps using that to direct future research, when it comes to research of the more scientific kind, like looking at things, looking at ways to change things, like quality of life improvements, things like that research that's looking to come up with things like that, rather than exploratory research can be more guided them by the priorities of the actual community, which I do potentially agree, you know, in theory is a good idea. And hopefully, is something that will continue to be helpful.

**Brett Heasman**

Thanks Sammy, how about you Carl?

**Carl Cameron**

I'd like to see a greater participation of autistic people in research and it be easier for autistic people to enter into research. What I'm talking about easy for people to go and kind of get published, I think, is one of the things I'd like to see, you know, it's a great to have an institution, it can quite difficult to get yourself kind of like noticed and that’s what PARC is about, the participatory autism research collective Damian Milton leads about getting autistic people, you know, we otherwise aren't attached to some sort of academic institution, be able to get their work published and be able to get noticed, I have a personal interest in an interest, an interest based account of autism what we call monotropism. So that’s my particular interest,

**Brett Heasman**

excellent. And I think maybe, you know, from my perspective, I'd like to see a more diverse ways in which knowledge is produced and disseminated and engaged with the academic process tends to go through what's known as peer review, where you write up your paper according to the conventions for doing so within your discipline, and then you submit it to a journal and then it goes out for review to experts, which is intended to be a very rigorous process. The challenge that is often your this knowledge is being published in places that can't be easily accessed, particularly by the communities that are being searched and also published in a way that's not accessible, using language and perhaps methodologies that are quite hard to grasp. And I think that, for me has been one of the challenges I've sort of grappled with throughout my career to date, which is how can we develop the knowledge in a way that's going to actually have meaningful impact because people can engage with it, they can interact with it, they can do something with it, or they can provide feedback about it. A live knowledge rather than something that's sort of crystallised in a paper somewhere behind a paywall is hard to reach. So I think for me, I would like to see social science have more established ways of sharing their knowledge and making it more interactive as well

**Carl Cameron**

benefit to autistic people, I think far too often sorts of academic sort of like to talk to each other, rather than talk to the kind of community and a lot of sort of, often very valuable research and very valuable data isn't, isn't disseminated out to the wider autistic community. I think it loses some of its value.

**Brett Heasman**

Yes, exactly. So it's, it's part of that process of trying to improve the alignment between the research being done and the priorities of the communitiesbeen research. Yes, a really good point. One final question, which is even broader than the last one, which is what do you think an enabling society would look like for autistic people?

**Carl Cameron**

I would say a society where adjustments have already been put in place where we've got environments that are already autism friendly, where there's environments in the classroom as an example that are considered autism friendly environments for autistic children, everybody else profits. I don't think that's the same in the workplace or, or anywhere else, where anyway, that sort of sensory adverse environments you know, I think everybody kind of like struggles you know, open plan offices is as an example, you know, they don't improve efficiency. They just save on brain space and they make life a living hell for autistic people and it's just probably lots of other people too. Often when we look for adjustments, you know, when we look for something small that's a you know, something to do with the environment often softer lights, you have the ability to be able to wear noise cancelling headphones also sit away main thoroughfares or hot radiators or windows where the lights coming through something like that. So an enabling society where when an adjustment is requested, that is not a big deal that it's not seen as being something that's, you know, a barrier that autistic people have been in some way kind of like difficult. You know, I mean, one of the the difficulties when Sammy was talking about before about functioning labels is a lot of people sort of like equate sort of like high functioning autism or sort of like mild do you know other people may experience “mild” autism but that’s not my experience of it. And when you look at the other end of the spectrum, and I don't know, you can't measure autism on a sliding scale, we need to think about spiking profiles rather than sliding scales. When you talk about somebody who is low functioning autism, you're dismissed. And you know its this deficit model where you focus on all the things a person can't do rather than looking at any kind of constraints, you got to sort of start moving away from that medical model, start thinking about the strengths of people, autistic people have. And have a focus on the social model, rather reductive model that we need to move away from

**Brett Heasman**

Thanks, Carl and Sammy.

**Sammy Williams**

I mean, I agree, I think just having a general level of knowledge in in most people about some adaptions, you know, that are reasonable, and that people, as Carl said, shouldn't be a big deal. Something like some of the things Carl listed that if requested, that should just be fine. I mean, just yeah, having a level of knowledge about some of the differences and difficulties that can be encountered by autistic people. I know, I find, like I said, a lot of people assume because I come across as being, you know, I know I don't have intellectual disabilities, I come across as being what people describe as high functioning. And that means they assume that, as Carl said, a lot of people equate that with mildness, and people assume that I don't then encounter difficulties. And then on the other hand, when people do find out about some of the difficulties I have, and problems I have that then colours their opinion of me, and they will make assumptions about my intellectual abilities and things and just knowing that they are discrete things. And it is true that people with autism can then have intellectual disabilities as well, but they're not the same thing. And that and that having differences in difficulties for me doesn't have impact on my other other areas of functioning that I excel at.

**Sammy Williams**

I don't get it often, just with people knowing I'm autistic, but then it's when they see, like, I know that people can think about what the idea they have in their head, they think, you know, oh, it's just a few differences, just basically the same as everyone else, but a bit quirky. And then then if they do see me having any difficulties or learn about anything, then they will change their opinion. And, and they will think it will colour their opinion on my other capabilities

**Carl Cameron**

see well the thing is you mask your way through on most occasions, even professionally, even within autism circles where, I feels safe. I will still mask my way through. I've been you know, I would be disingenuous of me to kind of say otherwise nobody really sees us on our bad days. I don't think

**Sammy Williams**

more so for people with autism. But I know that everyone will do that to some extent. But I know that people will depending yeah, on your competence at masking your way through, will just assume that you don't have any difficulties. And then when they do see anything like that, it will change how they think about you really. So just a baseline knowledge of the fact that these things are discrete, and that having difficulty in one area doesn't mean other things, I think would change people's lives and their abilities to you know, ask for help and adjustments. If they didn't think it would impact everyone's views on them.

**Carl Cameron**

I mean you really shouldn't have to fight for it should you, ot should just be automatic shouldn’t it that's the thing. No. And if you realise as well, like, you know, if you got sort of like, you know, if conflict isn't your thing, and its that's not the thing for most autistic people in general to mean, and you think you might have to sort of argue the toss was somebody who's maybe resistant to learning, shall we say that that's going to be a barrier, isn't it? That adjustment isn't in place, which might it might only tiny to the to whoever the line manager is, but the autistic person might be the biggest thing on the planet. It's

**Brett Heasman**

very true. Thank you for that fantastic insight. Yeah, I think as as you were saying, there whenever I've done autism training in the past, and it'll be the same for you, Carl, so I know you do it as well, kind of the first thing you have to do is myth busting, because so many negative stereotypes. Yeah. So if I was to wave a magic wand, it would be just to delete all those stereotypes in the first place, because they really are kind of the hurdle. And the stereotypes come from a number of places, science has contributed them, because, you know, we've had some unhelpful, sort of oversimplified ideas about what

**Carl Cameron**

Like all autistic people lacking emapthy

**Brett Heasman**

lacking empathy, being egocentric. Being computational geniuses, we get it from media as well, you know, the film Rain Man often ends up framing the way that people think about autism, when that's a story about a savant and savants are incredibly rare. We have only have about 100 documented savants in the world. So yeah, they're all the stereotypes, which autistic people have to navigate to, to even get to the point of sort of level playing field and then being able to say, you know, I need, particularly adjustments, as you were saying, often aren't, like massive things, but they make a huge difference for the autistic person. So yeah, that's, I guess it would be that it will be removing the stereotypes, but then just being less judgmental about people, I think all society would benefit from that.

**Sammy Williams**

Just in general,

**Carl Cameron**

that’s what they say, you make one adjustment for autistic people and everybody benefits

**Brett Heasman**

Absolutely, yeah. Yeah, I think humans form judgments, because you know, the world's socially complex, and they need to make some predictions about what to do. But that I think there's, you know, that there must be some ability to self-check and improve people's critical thinking about, you know, are they jumping to conclusions? Can they really know the person just by looking at them or observing their behaviour? But I mean, that's just an idealistic view, isn't it? You know, a world where people have empathy, equal levels of empathy which is never going to happen. the best thing we can do is just surround ourselves with good people

**Carl Cameron**

Well we get these tiny little bites of empty every now and again, it's called Autism hour. This is the promise of things to come sort of dangled in front of us for an hour, once a year.

**Brett Heasman**

So I think that brings us to the end of this podcast, I want to thank you both for joining and providing your really invaluable insight about this topic. I think this topic, although we've talked about autism in particular, I do think there are really wide implications for understanding other groups that have been omitted or had their voice marginalised or might be hard to reach. I think many of the things we're learning from the Sandbox project, we transport well to other contexts, so hopefully it's been it has wider significance for our listeners, as well. But yes, thank you both for joining and thank you, everyone for listening in. It's been a pleasure.