

“We need much better standards of research in autism intervention”: An interview with Dr. Damian Milton

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Transcribed by Julie Ann Lee

(Theme song – soft piano music)

ABK: **Dr. Damian Milton** is a sociologist and lecturer at the University of Kent on Intellectual and Developmental Disabilities through the Tizard Centre. He is also a consultant for the National Autistic Society in the UK, a project leader for the National Autism Task Force, and is involved in many other research and practice-related projects. His most recent book is *A Mismatch of Salience: Explorations in Autism Theory and Practice*. His theory of the Double Empathy Problem is bringing a paradigm shift to understandings of autism in the field.

Dr. Damian Milton, thanks for being here!

DM: Thanks for having me.

ABK: Let’s talk first about the Double Empathy Problem. For background, the diagnostic criteria of autism has traditionally characterized autistic people as having an impaired understanding of social life- this sort of standard way people talk of “missing social cues” and things like that, and this historically has been portrayed as a ‘**deficit** unique to autistic people’.

But in the Double Empathy Problem, which you coined and described in your work, we shift away from this old deficit model to something else. Can you describe this shift or what the Double Empathy Problem is?

DM: Yeah, it’s the **Double Empathy Problem**, where the phrase came from was originally trying to advise a parent group that I was involved with many years ago, and I was trying to explain that this kind of so-called empathy difficulties, or **Theory of Mind** difficulties were a two-way process. Theory of Autistic Mind often left a lot to be desired, as it were.

My background academically has been more in the areas of Sociology and Social Psychology, at least initially. And so when I was diagnosed myself and I was coming across this research around Theory of Mind, it just struck me as missing the obvious it would seem. That social interaction involves more than one person, and so empathy difficulties to me logically would be problematic for both parties, and so there’s more nuance in different contexts and issues that fed into that, but, as a base idea, that’s what it was driving at. It was a shift away from the deficit in social interaction being purely located in the mind of the autistic person.

That however creates a bit of instability over what exactly autism *is* in the first place, because of how it’s diagnosed and how it’s usually framed.

So, more recently there has been quite a lot of different experimental studies, pieces of research which have been testing various aspects of this out. There's the work of **Noah Sasson**, **Brett Heasman**, **Elizabeth Sheppard**, and **Danny Roper**. There are a number of researchers now looking at this area. Some work in Scotland with **Sue Fletcher-Watson**, and **Catherine Crompton**, so lots of research's now looking at this area and finding that *lo-and-behold* there are problems with non-autistic people trying to empathize with autistic people in various ways. There's more work to be done though, I think, in nuances, and how this'll pan out.

ABK: I mean the idea is that a non-autistic person is not really getting what an autistic person is experiencing or expressing *either*. Right?

DM: Yeah. I mean, there's qualitative evidence I've had in research where young autistic children are saying these things. A quote from one child in some years ago was '95% of people don't understand me.'

ABK: Mm-hmm.

DM: That was one example and quotes like this are very frequent in young children in school who were verbal and able to express that. And, often there's more comments like that in qualitative research than struggles to empathize with others, although there's also comments there. So, to me the picture of Theory of Mind is partial, at best.

ABK: Right, I think it's a generally agreed upon that "neurotypicals don't get it", and that's a common experience that people have. And it's funny that...

DM: Exactly, and when you talk about this with autistic people they know exactly what you're talking about.

ABK: Right. You've said empathy is conceptual and situational, and that's very true and obviously all the research is pointing that out as well, and that's a key point. But, so much of the autism intervention theory to date mostly has been about kind of what can be **measured** or judged from outside about a person, so the OT has a little chart and they tick off the chart and the measures of success and the benchmarks, they're all coloured by a lot of presuppositions in the field, based around this idea of Theory of Mind and this maybe is why a lot of neurotypical experts have missed the mark.

There seems to be a **perception problem** with how they understand autistic experiences and maybe more importantly how they understand the needs of the people that they're trying to serve. What they're measuring and the measures of success aren't necessarily what the actual people, for example a child, might really need.

DM: Yeah. I would agree with what you're saying there and if you think how one conceptualizes autism leads to how one then acts upon that information, so how to intervene, what to intervene with—[it] all follows from **how you frame autism** in the first place. Then how you measure it, or what you're measuring depends on those **goals**.

So, a lot of the outcome measures that are being used in research or practice do not equate well with the goals that the autistic people might have themselves, especially when you take into account this Double Empathy issues, and so there's a problematic, ethical issues about the goals of what

interventions are *for*. Whatever model one is using, what's the goal of it? What is it being used to try and promote, or not (as the case may be)?

ABK: Right. I mean a lot of the times it's a bit of an agenda, right? It's somebody else's goal.

DM: Yeah.

ABK: The goal for example of making a child appear "indistinguishable from peers" – they use those kind of phrases and that's kind of at the apex of their flow charts and intervention plans, but that goal is really shallow when you look at the real needs- the sensory needs and the emotional needs and all the other needs of the people that they're serving. I'm thinking particularly in a school setting, they want to have, you know for example with me they- the OT had me cutting out paper lanterns like every day after school because if I knew how to cut out a paper lantern, I would look like everyone else ...and I do believe she sincerely felt that that was what I wanted most of all- was just to look like everyone else. And, there were really *so many other things* I needed ...

DM: To fit in and...

ABK: You know that *wasn't* at the top of the list, and it's quite, quite something. And so, it gets into a sort of bigger issue of, well, what is **fulfilment** and how conceptual or situational or relative is this idea- or subjective is this idea of fulfilment? Because I don't think that they can really create good systems unless they really check in and have significant consultation with autistic people about what fulfilment might really look like.

DM: Yes. Quite. This is a big topic for me, I think, in terms of what is quality of life, fulfilment...what does that look like. Some things are perhaps somewhat commonalities between people- health and safety and security and life, a right to an education perhaps, but then beyond some of these base ideas, how someone leads a fulfilling life is highly subjective.

And in some of the work I've done I use theories- there's one I've used called **Personal Construct Theory**, which is all about how people construct and conceptualize the world themselves. So, it's using their language and their sense of the world to try to get in to that space with them, with their permission of course. Rather than imposing...some of the things you were talking about- the paper lantern stuff-- there's a misperception of the motivations of the child- why they are reacting or not to an activity or engaging in one or not. [That's] built on ideas which, from the non-autistic perspective and social conformity following the norm of fitting in, a consensus – all of these things are often highly valued in the non-autistic culture, sometimes for good reason. Sometimes that goes way too far, especially for people with disabilities or invisible disabilities and differences and the old goal of, as you said 'indistinguishable from their peers.'

I'm sure some who might listen to this podcast would say, 'oh, we're- that's not what we do anymore' and 'we don't do that.' But, it's more subtle in a sense rather than a clearly stated goal as it once was and still is for some like **Ivar Lovaas** and his followers. It's more subtle normalization [that] somehow a fulfilling life will come from fitting in and behaving like other people and so on. And this can become quite oppressive for people who either don't know how or do not wish to for whatever reason.

And sometimes this sanctioning of 'abnormal' behaviour if you like, is quite ridiculous as to what people are getting concerned about, and then you're imposing on autistic sensibility without taking those needs into account, quite often. In any kind of intervention, educationally- psychological therapies, whatever if the goal [does not take] those autistic sensibilities into account, you're quite possibly going to harm people and do damage.

[14:57]

ABK: Right.

DM: I think that's a problem for practitioners working with autistic people everywhere. *Trying not to harm people* should be number one priority ethically...and working to enable and empower that trust and rapport in that relationship rather than imposing and sanctioning and so on. But all too often in practice, that's what we see - restraint, seclusion and so on at the extreme end; that unfortunately happens far too often.

ABK: Right. I think in terms of accountability and ethics it's pretty new for these issues to even be talked about, and I think a lot of that is come out of the Disability Rights Movement and Autistic Self Advocacy Movement calling for **accountability**, but there's a long way to go because it's a really entrenched system. And I was wondering what you think, because you're a parent. I'm also a parent and we both are parents of autistic kids as well. So, we have to relate within the existing system of services and watch for change that happens very, very, very slowly--at least here in Ontario. I'm wondering what your perspective is on where we're at, and where we could be going in terms of these early services to make them better?

DM: Where we're at, I think, is still not a great place from my point of view. I think there's a lot of this ideology of a '**window of opportunity**' of child development and if you get in in the early years you'll be able to modify that for the better somehow, in a very normative way. But I think it's very **problematic**, and I think yes you can ideally get supports in, and understanding of that potential development, but then with so much diversity on the spectrum, it's hard to know in those early years *how* someone is going to develop.

That's another thing is with interventions: a lot of the time people will claim that the change is *because* of what they've been doing to support that child or what have you, when really it's the child just maturing and developing or growing older...

ABK: Yeah.

DM: ...and they may have got to that point any way.

ABK: Or *despite*! Or *despite* the intervention.

DM: Or despite it. There's often an assumption that one has more control over a situation than one really has, or the opposite- one doesn't know one is having an effect when one is. So there are a lot of issues when it comes to intervention and interpretation of what's making the change, and there's often a **confirmation bias** there that if you're putting in all this effort, then it must be doing some good.

ABK: Right!

DM: You see what I mean?

ABK: Yeah. What is the evidence, really? How can you really...

DM: Exactly. So the way to change this is to, on a number of levels we need more **participation of autistic people** into support strategies, what they're for and how people are treated, and in a meaningful way, not a tokenistic one. We need much **better standards of research** in autism intervention.

ABK: That's right.

DM: There also needs an implementation in practice. Practice can be messy, you might make mistakes, you need to be **reflective practitioners** and **humble** in your practice. I think the very best practitioners are humble when they meet a new person and want to get to know that person, and what motivates them and what sensitivities they have and so on. A poor practitioner would be someone who thinks they know it all and can just apply a model and an intervention, and that's what you do with autistic people-- tick a box. So...(laughs)

ABK: (laughs) Well, in ABA, that's pretty common. I mean the outcome measures in ABA aren't measuring things like happiness and fulfilment!

DM: No, not often, and if there's an **overconfidence** in the intervention and the method, this is problematic- or their application of it.... For me I have deeper issues on the theory and philosophy of **behaviourism** about human minds and learning. I think it's oversimplified and often over-reductionist as it were, and an over-reliance on that theory leads to people not looking at ...cognitive theory or subjective ideas around quality- qualitative studies around quality of life- what it means to be autistic, what it means to have an autistic good life. So ...cognitive theories are often ignored as well, so whether they're the old ones like **executive functioning**, or newer ones like **predictive coding** that are being applied. ...

ABK: Oh, yeah. Sometimes only certain aspects of behaviourist theory- the most problematic aspects.

DM: Yeah, or a simplified version of behaviourist theory when it comes to implementation in praxis which, if married up with this normalization or imposing approach from a practitioner...often if they're not well experienced or under-confident themselves they might actually do more wrong. It's a kind of heady cocktail I would say for **potential harms** there when it goes wrong, and often that isn't acknowledged enough by those who are practicing it or the researchers in that field.

It's often sold as "behavioural support is good for you and it's 'evidence based'" and blah blah, and it's overselling the case by *quite a lot*, and not mentioning the potential downsides or when it goes badly wrong. ...One also needs to be self-critical, whatever theory and practice one is using.

ABK: I don't think they're really *comparing* [their ABA practice] against anything. Isn't that part of it as well? In the studies that I see that are coming out, besides the bias issues and all the issues that you've just mentioned, they don't have a [control group], another group of people that aren't doing [ABA] that they are really actively comparing it against. ...I've *never* seen a study that compares the kids that are 30 hours a week in the ABA centre versus the kids that got to play. Where's that study, you know?

DM: Well there's often in these studies what's *called* a "control group" and there's said 'practice as usual' and things, but these are hardly ever explained what that means or where this practice is happening or who's conducting it. Sometimes, you get a bit more information on that. But, often it's not compared to an alternative practice model and I'd love to see an autistic informed practice model being fully tested in this way. But if we were to compare models, then you'd have to agree upon outcome measures that were meaningful (laughs) which is not happening either!

I would say a lot of the issues go beyond the evidence to ideological divides and controversies. This goes back to how autism itself is being **framed** and **defined** as a deficit, as something in need of remediation. A 'medical model' problem or a way of being which can be highly disabling in the societies we're in and what can we do to help support and accommodate these needs --a more **social model approach**, as it were. And I think that the combination of that mindset and framing with a more person-centred autistic informed practice would ultimately lead to better quality of life and fulfilment on people's own terms.

ABK: Right.

DM: This goes beyond those who are on the autistic spectrum who are highly verbal, or articulate. My son would be classified as having a severe learning disabilities or intellectual disability, but there are ways of working with my son which lead to him being safer and more fulfilled and interested and engaged, and that means getting to know him, what interests him - his sensory sensitivities are very strong, and what his likes and dislikes are. That takes time and effort in engaging with him, but do you see what I mean?

This kind of ethos needs to be central, because another key area is I think around **stress** and the perception of threat and the fear and anxiety and so on, and so if one is not aware of that happening in trying to teach or trying to do anything in a learning environment ...say with a young child, if they are overly stressed, they're not going to be able to learn anything.

If the school environment or the teaching method is adding to that stress, then you're not really creating an environment which is going to be educationally fulfilling and engaging for that child.

ABK: Sometimes in the classroom setting, I mean it's really ad hoc here in Ontario...teachers will sort of *try things* but in terms of a real accessible design in the classroom [where] students can feel comfortable- all students can feel comfortable, we don't have that. There's really a lot of money around autism in my province and elsewhere, and the money isn't going very much or at all towards that kind of goal of making learning spaces comfortable. And some of those ways to do that are quite simple-

[30:03]

DM: Mmm.

ABK: -but just not being done, and you're right that when the stress levels are so high, I mean you can't [teach]-- it's like just putting on Band-Aids.

I wanted to ask you about your work, where it's being incorporated into training programs for ...Studio 3's Atlas Program at Autism Synergy Program and among others. How are these new programs different from the earlier type of programs in that way?

DM: The Synergy Program by AT Autism, and the Atlas Training by Studio 3, those two in particular are training or creating practice models which are similar to what we've just been talking about, where autistic people like myself have been involved in the development and delivery of this. And there's highly experienced practitioners, but with a different framing as to how to help autistic people, which is far more around the environment and often the behaviour of the *people around the autistic person*. They're ...training people who've had a behaviourist background, so one thing one can do is turn the kind of direction of **who's looking at whom**. And how does one look at the stress levels of staff in a care unit or something like that, or teachers for that matter...the stress between the child and the staff? And they also would look at "why not use your behaviour checklist that measure the antecedents of *what makes this child smile or laugh?*"

It kind of shocks people because they're so used to watching for the *problem*--the crisis, the challenge, the meltdown-- rather than looking at what is fulfilling for that person. Also it's more informed by cognitive theory, autistic input, and all of that, and it makes a big difference. ...It's having autistic input in a meaningful level in the training. And from experienced people....people who also work in the field who may be autistic themselves too. A lot of autistic people are also parents, or also professionals and have a lot to add, particularly if we work together on these things which is possible sometimes, (laughs) so.

ABK: I want to relate this to an issue we have in the autistic self-advocacy movement, because you're talking about autistic people being consultants and we're certainly working *towards* that but I think sometimes that we're being told by some parents (not all, but some parents) through this myth of the **functioning labels**- high functioning, low functioning and this sort of binary ...[we're being told] that we can't understand their situation because we're at different levels or we're not "severe", we're "not like their child", and of course the self-advocacy movement does represent and have the full range of disabilities and needs within our community.

I'm wondering like what your thoughts are about that connection and also why there's resistance to accepting the connection among us in the consultation process?

DM: Yes. It's (sigh)... I think the 'you're not like my child' and that kind of thing....well, they're not like *my son* either – even less so (laughs), and one of the problems with this thinking is there's no connection or cultural connection so, often it's a disagreement around how autism is being framed.

...There's often assumptions that [autistic self-advocates do not have support needs] which is a bit strange to me cause I've met quite a few [that do]...or that we wouldn't be working as practitioners or professionals or with wider groups of wide a range of needs. And so many autistic people I know have an affinity with autistic people across the spectrum as it were, and work as practitioners, work with children, work as researchers – are working to improve the lives of autistic people with high support needs because they can see the distress that people are often under and relate.

Me and my son would appear very different on first impressions to an onlooker, but that doesn't tell you much about how we would *empathize* with one another. This goes back to the whole double-empathy thing. And, because autistic people can empathize and relate with others who might have similar dispositions, similar experiences, similar interests ...the lack of empathy thing is a myth. And yeah, say on sensory sensitivities both me and my son have very high sensory sensitivities to external things...

lights, smells, sounds... So, often I'll be very quick at understanding what's upsetting him in a given context, whilst other people wouldn't be. Yes, that partly comes from being his parent, but also comes from having those same sensitivities myself. So, without those- that ability to empathize with him, I'd easily miss that.

ABK: Right.

DM: So the idea that more verbal autistic people don't have anything of value to share which may be of use to those with less verbal abilities or whatever, is wrong. And yes, you do have autistic people who may not have come across in person like my son, they may be younger people, activists or what have you. They may not understand the situation this particular parent is in, but often it's used to undermine the position the autistic person is advocating for. Do you see what I mean? If they are agreeing with them, they wouldn't be saying 'you don't speak for me' – they'd be saying 'Oh, I empathize, I can understand where you're coming from.'

ABK: Right, right.

DM: So the problem is ideological.

ABK: I think you're right. It's at the core of it. I'm gonna shift- since we're talking about play and how we play and how delightful it is to play, I'm gonna talk a little bit about your discussion of **flow states** because this seems to relate to play. You write that what neurotypicals would call 'repetitive behaviours' can be interpreted very differently- are interpreted very differently through the idea of the flow state. Could you state more about the flow state?

DM: The idea of flow state though is when you're **completely absorbed** in an activity ... if you think of an activity you particularly enjoy or are particularly engaged with, you can become so absorbed that you lose track of oneself, lose track of time, you become in this sense *in* the activity. Sportspeople might call it being 'in the zone'. You're so focussed and all your attention is matching up well. Sometimes this can be achieved through a challenge, as long as the challenge isn't too much or too difficult, meeting a challenge as it were, learning something new.

Being in the flow state can be something brought about for autistic people particularly through predictability and having control over an activity, in a sense *playing*, but in a controllable way. I think the autistic perception is often one which is fragmented, somewhat overloading, difficult at times to make sense of the world when there's too much going on to process. So, honing in on what is predictable and controllable reduces stress and so some of the repetitive behaviours and stimming is stress-reducing activity. But also the passionate interests that autistic people have in particular things can be ways of getting into a flow state.

Something I do when training practitioners about autism is I ask them what it's like when they've ever tried to interrupt an autistic person when they are fully engaged in an activity. And, usually they caught on quite quickly as to what you're talking about. Because say that flow is interrupted, for an autistic person, you can go from a place of safety and everything is how it should be to the complete opposite. So, that kind of makes sense to people, that that can be a highly stressful thing to do to someone.

ABK: Right.

DM: And so, there are ways if you explain things like that that people can start empathizing a bit better than perhaps they might have done before if taking things like that on board as well. What people do to achieve the flow state may differ from one person to the next, so it's quite related to interest and attention and areas like that.

ABK: I think that understanding flow state or being able to get into a flow state or that are being able to connect in a flow state *together* which I certainly do with my son around various things especially when we're out at the beach or other places like that... maybe that's something that as we learn more- think more about flow state, joining in flow state with a child could almost be *taught*. Or the whole idea could be taught to people, so they have an empathy [about] it and also an ability to experience it on some level even together.

[45:01]

DM: I think there are some interventions with what's called **intensive interaction**, which I would have some issues with, but it's heading more in that direction. It's more about relationship building, rapport building, and getting inside the child's world and understanding where they're coming from and working with that and so on, and I think there are practices which are heading in that direction as an idea.

In terms of **mutual flow** or a kind of social flow between people, this is very important I think because the Double Empathy Problem is a breakdown in mutual flow. It's a breach if you like...a mutual incomprehension which can get very bad in some situations, for both parties. But if you think of mutual flow, for a lot of non-autistic people they'll find that in small talk with one another.

ABK: Ah.

DM: They'll lose track of time and just talking nonsense about the weather. Or maybe that's a British thing, I don't know (laughs).

ABK: (laughs)

DM: And then so you can have mutual flow in social interaction, but there are other ways of finding social flow with people: if you think of music and a jam session, the musicians may be communicating through the music they are playing and bodily gestures and nods and so on. And, very few words being spoken at all. That is a mutual social flow, one that would probably suit some autistic people that much better than a group social interaction using words. So, if you think creatively about how to engage with this person's interests, what drives them, then finding a mutual flow is a lot more likely and that's with both verbal and non-verbal or less verbal autistic people.

ABK: Mm-hmm.

DM: Yeah. (laughs)

ABK: (laughs) Well, I hope there's more- I hope you do more work on the flow state and all the work that you're doing. You're part of a wave of scholars that are moving us away from this older idea of centring the norm where difference were always being seen as deficits [towards] more of a positive understanding of difference and also of reciprocity which seems really, really key.

DM: Yeah.

ABK: Yeah.

DM: I'd have to agree with you there. I think we still have a long way to go, but looking at reciprocity and the context, the environment and what's meaningful for that person, and how they communicate that and so on... It's being a lot more respectful of autistic ways of being and *working with* that rather than trying to take away the autism somehow, as if it's something separate to that person which a lot of the old models try to do.

ABK: Right. What would a new model look like? What are they starting to look like from what you're seeing?

DM: Person-centred, humble, focus on learning from autistic experience, building local capacity with practitioners, so instead of bussing in the so-called expert at vast expense to do an hour of work or training, it's to build up the understanding, confidence and knowledge in a workplace, and that needs a bit of a culture shift really, and, from across an organization.

And I can see this happening in certain schools or place of care where the leadership all the way through the culture of that place is a good one and they're really helping people as best they can. and I see others where the culture is horrendous really, and often it's the leadership which is somewhat at fault and I would say not seeing the real issues for what they are. And sometimes I think there's the perception of **risk** and management of risk often motivates people. But, the more you try and manage a person as if they are just *a risk to be managed*, the less trust they're going to have in you and the more you're going to break down that trust which actually adds to the actual risk (laughs).

ABK: That's right (laughs) yeah.

DM: And so, if people focus more on trust and relationship building, that would be beneficial.

Unfortunately, the very things that do that are sometimes the things which are least well-funded or [face] the threat of being cut. An example in the UK is one-stop-shops which are kind of community centres where you can meet others, get information, and so on, where and if there's kind of community support and intervention is highly valued by people in that community, and people may not hit a crisis point and need very expensive mental health support. Yet, the crisis support is what's being funded, however badly it's being done, and that more social preventative stuff isn't being. Do you see what I mean?

ABK: Right. We have the same thing here.

DM: Yeah, and it's that kind of culture shift and focus of *where* the investment is going and *how and why* which really needs looking at. Which is on a policy – political level, and the valuing of social supports and services.

ABK: Yeah. It's something where personally here in Ontario, we just are starting to get our foot in the door as our organization- my organization is 15 months old and we're competing against- for example ABA, they have a lobbying firm. They have a *big* lobbying firm with a lot of money and they have a package which appears easy to understand and they're able to sell [it] to policymakers. But we [disability rights activists] don't have a lobby and I think everyone in the disability communities are starting to

coalesce at least as an interest group to put these interests forward, because we're a bit too siloed now with the various community programs to compete with the level- the volume of [the ABA] lobby.

DM: It's an industry.

ABK: Mm-hmm.

DM: Where there's money to be made- in vested interests, a challenge to that would be seen as a threat to them. That's why they often do not like being criticized for what they're doing. And so, it's a very difficult thing to do, but yes, we do need to organize and work with others so it's not just autistic people or disabled people. There are practitioners and parents who would agree with our way of thinking perhaps on these issues, and it's creating a bit of lobbying pressure at a political level but using evidence and rationale, so that does mean I think at times critiquing the work of others like the ABA lobby and show what the issues might be with the in a respectful, credible way. Not just saying it's all bad, it's all abuse or whatever. Just these are the issues and criticisms that have not been answered and one of the things that does annoy me somewhat is that often I see articles by behaviourists answering criticisms that aren't really being made.

ABK: Yeah. I see that. I know.

DM: (laughs)

ABK: (laughs) yeah.

DM: Or mis-framing criticisms, oversimplifying them and not actually answering or attempting to [address] the very real issues that there are --and it's that kind of thing which is difficult to deal with. But I think the way forward is to show policymakers the actual evidence base [for ABA] which is pretty poor, make an argument around the goals of intervention and what supports strategies should be trying to do so, around outcome measures and so on. Making the case for participation *ethically*, and then hopefully the quality should improve over time.

We also need better standards of research and to support policies...one thing we're seeing time and again is a widespread usage of things which are not well supported, but it came to be and they often don't have the support of the very people that you're intervening with.

ABK: Yes. That is very, very common.

Can you talk a little bit about what you're working on currently?

DM: I'm currently chair of a network really called the Participatory Research Collective (or PARC for short) and it's really a network promoting the participation of autistic people in the research itself, the design of and carrying out of research. Whether that's becoming researchers like myself or people just interested in research and having a voice within it who may not be academics themselves. It's promoting participation at a meaningful level.

I'm also a project leader for a group called the National Autistic Task Force in the UK which is a small group of autistic people who are --we're quite experienced as a group in different areas and we're trying to influence policy guidance and practice and so on at a better, more informed level than has been the case in the past. Just putting pressure on and being critical, being a group that can put in to

consultations on policy documents and so on. So, it's being seen to have that voice and put that across. In the future, research-wise I'm interested in more practical work around sensory issues and the sensory environment and adapting environments and what impact that can have on quality of life for say autistic children in schools and so on. So, sensory in areas is one area and-

[1:00:03]

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DM: - But also an interest of mine is linking up work around interest and attention and theories such as **monotropism**, and in the works of Diana Marian, Mendelson and people- matching that up with Double Empathy issues and also work that's happening in more neuroscientific fields around what's called Predictive Coding Theory and there's a growing interest in applying those theories in the field of autism.

ABK: Oh, interesting.

DM: And I think the coming together of autistic voices with neuroscience could be quite interesting. It's a bit of a mouthful, it's called **Neuro-Phenomenology**... new field, but phenomenology being more qualitative, interpretative work around subjective meanings and experience and the neuroscience bit. Bringing these theories and ideas together, they're working across disciplines to create a different model of how we see autism itself--or neurodiversity, for that matter. I think that it is possible, especially in the academic work field around this. And I think where there are ways of working with others that can be beneficial, we should be doing so. I do think there are others in the field that I wouldn't be working with for various reasons but where positive things can be done that will benefit the community then great. I'm all for that, but I do have standards (laughing)

ABK: (laughs)

Well sometimes it's easier to go across the disciplines, because you have people who are a little bit more of a clean slate and a different type of perspective, and aren't so embedded in some of the older ideas.

DM: (sigh) Well, I think that's one of the problems in academia in working across disciplines but just because it can be difficult doesn't mean it shouldn't be attempted especially when you're looking at people in applied topics- how to support people this is a multidisciplinary exercise.

ABK: Yeah.

DM: I think that it is possible and we can make improvements but there are also barriers to that and the vested interests and so on of lobby groups and things- it's not easy.

ABK: Definitely.

It was so interesting speaking to you about all of these ideas and also about the work that you're doing in academia and beyond academia. All really important areas to be working in and I want to thank you so much, especially for coming on the program and everything that you do.

DM: And thank you, and I wish you all the best for your efforts in Canada.

(Theme song – soft piano music)

ABK: We were speaking with Dr. Damian Milton, a sociologist and lecturer at the University of Kent. He spoke to us from Kent.

ABK: You've been listening to Noncompliant. I'm your host **Anne Borden King**. Noncompliant was recorded at MCS Recording Studios. Various episodes were engineered by Nathan Gravette and TJ Liebgott. Thanks to our engineers and thanks for listening