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Debate 1. Does autism have an essential nature?

Damian Milton, a sociologist and activist and Sami Timimi a child and adolescent psychiatrist

The essential nature of autism (and the merits of diagnosis) in a series of emails in summer 2016 before an initial meeting of the Rethinking Autism Network (RAN).

Sami Timimi:

I have read articles by you, Larry Arnold, Dinah Murray and after your email had a quick browse of the 4 issues of 'Autonomy'.

However, none that I read have addressed the problem of 'essentialising' that happens when you assume that there is something out there in the real 'natural' world that is inscribed in your biology as a constant and specifically 'autistic' entity and that there are people who 'know' (whether its experts or self diagnosers) how to discover those who have this specific entity and divide them away from those who do not. The idea of dividing humanity into 'neurotypical' and 'neurodiverse' and that such a categorical division is possible is different to medical diagnostic discourse only in its value judgements about such categorical divisions. The movement you have identified with fits very comfortably in a medical model framework and therefore can do little to challenge the dominant social constructions of medical and psychiatric practices. It accepts uncritically the idea that there are essential and knowable biological differences that construct our social identities and behaviours. It cannot from such a starting point adopt a meta-perspective that is able to question why 'autism' emerged (as opposed to being

discovered) as a phenomena and became so popularised in the last few decades and what this social and cultural phenomenon might tell us more broadly about political, economic and cultural developments. Whilst the neurodiversity movement has helped with combating stigma and negative stereotyping it can only do so for those like you who are happy to self-identify with a pseudo-scientific construct – many can't and don't want to (like many young people I see), for whom something more helpful appears to have been explaining that autism is just a description and doesn't mean anything more than that, searching for exceptions to the diagnostic descriptions, to help a more complex idea of a person to emerge and undiagnosing those who wish to (let's face it you can't 'undiagnose' someone with heart failure, but because autism is a construct that emerges primarily out of the imagination of the diagnoser with no biological marker, it's possible to do that in autism – doesn't that tell you something?).

If I were to use a political analogy (which I'm sure I'll end up regretting), Neurodiversity is a bit like the soft left, who accept neoliberal capitalism as the 'natural' dominant system by which economies have to be organised, but want more protections compared to the soft right – but neither see the whole framework of neoliberal capitalism as the root of the problem. That's why I don't think there is anything particularly 'critical' about your approach. From my perspective I have rejected as a scientist and practitioner the notion that there is any firm knowable biological entity called 'autism' (and I would like to see what evidence you can bring forth to argue otherwise) in the same way I have rejected the idea that neoliberal capitalism holds the solutions to our current social, political and economic crisis or can do anything constructive about the gross inequalities we have in our societies.

Damian Milton:

“...coming back to you and your colleague’s articles, none that I read have addressed the problem of ‘essentialising’ that happens...”

Then you have not read widely enough.

“...when you assume that there is something out there in the real ‘natural’ world that is inscribed in your biology as a constant...”

None of the above writers see autism as a biological constant ‘out there’ in the real world that can be easily defined and bracketed, but as a social construct. We do talk of embodied diversity and subjective experiences though.

“...and specifically ‘autistic’ entity and that there are people who ‘know’ (whether its experts or self diagnosers) how to discover those who have this specific entity and divide them away from those who do not.”

None of the above writers do so by reifying the dominant medical models of autism, but talk of a social grouping and with a great deal more nuance than you are describing:
“What I have come to understand is that autism is not one single invariate thing.” (Arnold, 2004).
What we argue is that there are differing social positionings that occur such as those diagnosed, those who are not who wish to, those who are who don’t and so on. Where we may differ is perhaps on regard to embodied diversity and experiences and their relevance to the debate?

“The idea of dividing humanity into ‘neurotypical’ and ‘neurodiverse’ and that such a categorical division is possible is different to medical diagnostic discourse only in its value judgments about such categorical divisions.”

Nonsense...

The division between neurotypical and neurodivergent (not neurodiverse) is an arbitrary and social one (I have been arguing such distinctions to be social conventions since the 90s but never mind). The term neurotypical originated as a mickey-take of the way medics describe ‘autistic people’ – for me it has come to mean an idealised fantastical construction of neoliberal ideology – the ‘mythical norm’ (but you seem too busy putting theories into other people’s minds perhaps?). Yes – there are ‘autistic people’ who see this as distinct biological line – not me – and not many others. “Extremes of any combination come to be seen as ‘psychiatric deviance’. In the argument presented here, where disorder begins is entirely down to social convention, and where one decides to draw the line across the spectrum.” (Milton, 1999 – spectrum referring to the human spectrum of dispositional diversity). “Thus in this formulation, there is no neuro-typical to deviate from other than an idealised fantastical construction of Galtonian inspired psychological measurement.” (Milton, 2014a).

“The movement you have identified with fits very comfortably in a medical model framework and therefore can do little to challenge the dominant social constructions of medical and psychiatric practices.”

Your argument over generalises the views of an entire community and movement as one static thing – this is a nonsense and silences critical autistic scholars who have been deconstructing such labels

for many years from a perspective of someone so labelled – this to me and others is thus a highly damaging narrative to be extolling.

“It accepts uncritically the idea that there are essential and knowable biological differences that construct our social identities and behaviours.”

No it does not !

“It cannot from such a starting point adopt a meta-perspective that is able to question why ‘autism’ emerged (as opposed to being discovered) as a phenomena and became so popularised in the last few decades and what this social and cultural phenomenon might tell us more broadly about political, economic and cultural developments.”

Other than writers were discussing such issues (like Martijn Dekker and Larry Arnold) long before Nadesan was. A history that you are furthering to obscure.

“Whilst the neurodiversity movement has helped with combating stigma and negative stereotyping it can only do so for those like you who are happy to self-identify with a pseudo-scientific construct”
Again – I don’t, I reframe what autism ‘is’ against dominant theories, as do the other writers mentioned. We identify with a social construction and identifier and reinterpret its meanings – clumping us all together and dismissing us by creating a straw man argument only creates anger and frustration at the numerous mistakes you consistently make (and then are referenced by others – another horrendous example being the Jassma and Welin piece).

“...explaining that autism is just a description and doesn’t mean anything more than that...”

No – nothing is ever ‘just a description’ – especially when people labelled autistic die decades early (recent Swedish report) – as just one example. Discourses have consequences – as yours of the neurodiversity movement without sufficient interactional expertise with such communities does to.

“Neurodiversity is a bit like the soft left, who accept neoliberal capitalism as the ‘natural’ dominant system by which economies have to be organised, but want more protections compared to the soft right – but neither see the whole framework of neoliberal capitalism as the root of the problem.”

Utter rubbish if you don’t mind me saying so. Neurodiversity means that all humans have diverse neurology and that has an impact on embodied experience. I think that is where we may differ? Although I find it hard to see how one can argue against that. Your characterisation of the neurodiversity movement is wholly inaccurate – at least simplistic in the extreme – and thus is like a man describing feminism as a static and singular mode of thought based in neoliberalism etc. and for me should be called out and criticised for it. Seeing as Insel, London, Gillberg et al. would agree with you about disbanding the label and going with dimensional scales of deficit are more in keeping with your way of thinking currently? Seems neither of you are paying much attention to autism as a cultural identity marker, the social lives of those so labelled, their variety of views and experiences, and so on.

“That’s why I don’t think there is anything particularly ‘critical’ about your approach.”

That is because you have little idea as to what my approach entails – which bounces around phenomenology, Marxism, and post-structuralist ideas (but heigh ho).

“From my perspective I have rejected as a scientist and practitioner the notion that there is any firm knowable biological entity called ‘autism (and I would like to see what evidence you can bring forth to argue otherwise)...”

Lol – that is because I was arguing it wasn’t long before you were!

“...in the same way I have rejected the idea that neoliberal capitalism holds the solutions to our current social, political and economic crisis or can do anything constructive about the gross inequalities we have in our societies.”

Funny that – me too! I think I will leave the last word here to Larry:

“Notwithstanding the difficulties we face as a marginalised group making inroads into the academic disciplines, it is so often the case that those disciplines themselves exist within silos, failing to understand the contributions that other disciplines have to make on each other.” (Arnold, 2012).

Sami Timimi:

I like your answer! I can hear your passion and your frustration at feeling that I have missed the more nuanced position you occupy and your alertness to multiplicity, diversity and your wish to avoid simplistic identity politics. I suspect you are right that I haven’t read enough nor have I read with sufficient openness and sensitivity and you then (rightly) fear this leads me away from connecting with real lived experiences of those who are labelled with autism. If this is partly what you are getting at then fair point and it makes sense then your feeling that there should be more representation from those with lived experience.

However, the central problem remains and I can’t see anything in what you have written that is able to deal with this. In your writing you use a concept of the ‘autistic person’ and refer to yourself as being ‘on the autistic spectrum’ and others who are ‘on the autistic spectrum’ or is an ‘autistic person’ – If you really see autism as a social construct then how do you get to there being something ‘essentially’ different that marks out an ‘autism community’ or ‘autism communities’ or ‘autistic person’? Where do you imagine this particular difference comes from (it can’t be geographical, language, tradition, age etc. that are the more common markers of community)? Is the commonality the doctors who diagnose it (power over knowledge), the ‘idea’ that there is something different (social construction i.e. choosing to focus on a specific aspect of a person for a particular purpose), something inherent in the embodied experience (biology) that means that the person labelled autistic has unique experiences of the world that cannot be similarly experienced by someone who is not an ‘autistic person’ (in which case how do we figure who can or can’t relate to the embodied experience)? In other words how do you get to the ‘autism’ in the autistic person? Of course I am mindful I have laid the problem out in categorical and dualistic terms, but this is intentional in order to help understand how you figure the epistemological/ontological basis on which you have arrived at an acceptance of there being such a thing as the ‘autistic person’ (as opposed to the person who has been diagnosed with autism).

Damian Milton:

Hello Sami,

It seems we may be getting somewhere with this debate now.
“...alertness to multiplicity, diversity...”

Yes – I would argue that a number of ‘autistic’ scholars are alert in this respect.

“...and your wish to avoid simplistic identity politics.”

There was an interesting and critical presentation that talked about this at Autscope the other week by Martijn Dekker. There is a trend toward identity politics within ‘autistic culture’, which is a bit simplistic, but this is not hegemonic within the community within the UK imv. There is a worrying trend I see on social media and from some aspects of US-based activism though (particularly around arguments about facilitated communication – where I am more in line with Mark Sherry’s recent article on the matter).

“I suspect you are right that I haven’t read enough nor have I read with sufficient openness and sensitivity and you then (rightly) fear this leads me away from connecting with real lived experiences of those who are labelled with autism. If this is partly what you are getting at then fair point and it makes sense then your feeling that there should be more representation from those with lived experience.”

Not exactly no. I do think that you could do with understanding more of the diversity of views within ‘autistic culture’ that have arisen and be more respectful of this history, particularly in regard to critical theorists who have been so labelled or who so identify for whatever reason. I think there should be thus more open invites to ‘autistic’ critical theorists who have been doing such work for some time or who have some interesting views to contribute to such discussions (like those previously mentioned by me).

“However, the central problem remains and I can’t see anything in what you have written that is able to deal with this. In your writing you use a concept of the ‘autistic person’ and refer to yourself as being ‘on the autistic spectrum’ and others who are ‘on the autistic spectrum’ or is an ‘autistic person’ – If you really see autism as a social construct then how do you get to there being something ‘essentially’ different that marks out an ‘autism community’ or ‘autism communities’ or ‘autistic person’? Where do you imagine this particular difference comes from (it can’t be geographical, language, tradition, age etc. that are the more common markers of community)?”

Why not? In an article I did in 2014, I explore to what extent the breakdown in interactional expertise between ‘autistic’ and ‘non-autistic’ people is cultural or embodied in nature. Of course, one can probably never adequately answer such a question, but I did propose that I suspect that in many respects the barriers are cultural ones that can to some extent be bridged (at least where there is some kind of mutually communicable use of language). The use of language and perceived semantic meaning is an interesting area with regard to the ‘autism spectrum’ though. So, if I had to say what the essential difference is, I would say that autistic culture is a subculture that has developed in reaction to being so labelled and the various constructions of ‘autism’. I do think there are also embodied differences between people in terms of ‘disposition’ though, and that some of this has a biological aspect. For instance, for a simplistic example, I have no idea what it is like to have a life threatening illness (as yet). Back in the 1990s I used the phrase ‘the human spectrum of dispositional diversity’. This was before I knew much about the construction of autism other than having watched Rainman etc. This was partly in response to the numerous psychiatric labels I

acquired as a teenager. Yet, I was arguing (and still do really) that whatever the embodied and cultural differences that influence a person's disposition, that those deemed outside the ever-narrowing 'norm' were discriminated against in numerous ways (e.g. I was bullied and marginalised due to my perceived otherness long before I was diagnosed as autistic). Indeed, such a discrimination and resultant psycho-emotional disablism may be the most common factor amongst 'autistic people'?

"Is the commonality the doctors who diagnose it (power over knowledge)."

Well – this is a big one! It is realised that the community / culture as such would not exist without changes to diagnostic criteria and culture. At the same time, much like in 'Mad Studies', there is often a revulsion of having been somewhat defined by the medical fraternity (this also came up in Martijn Dekker's recent presentation). There are of course issues with 'self-diagnosis' (if not in personal identity terms than in practical terms) and especially if people take it upon themselves to identify/diagnose others. The community seems to be more galvanised around ideas about those who are 'neurodivergent' (although with the idealised notion of normalcy this could include just about anyone!). But as I say, this is often coming from an experience of embodied/cultural 'otherness' of some kind.

"...the 'idea' that there is something different (social construction i.e. choosing to focus on a specific aspect of a person for a particular purpose), something inherent in the embodied experience (biology) that means that the person labelled autistic has unique experiences of the world that cannot be similarly experienced by someone who is not an 'autistic person' (in which case how do we figure who can or can't relate to the embodied experience)?"

To me, this is a matter of interactional expertise (see my article from 2014 on this) as I would 'theorise/model' it. There is little empirical evidence in this regard, but some work by Liz Sheppard et al. recently found that 'non-autistic people' struggled to read the emotions of autistic people they watched on film. This suggests that 'theory of autistic mind' may leave something to be desired too. So, why is this? Is it purely a cultural phenomenon? To me, this is unlikely. To say there can be mutual incomprehension between people of differing dispositions seems fair to me (although that can be for whatever reason – e.g. watch a conversation between 'techies' and 'non-techies' within a project team for a simplistic example). Just because I think there is 'neurological diversity' and that impacts on disposition and experience, the category of 'autism' is at least somewhat arbitrary.

"In other words how do you get to the 'autism' in the autistic person?"

Like asking how does one get to the 'gay' in the 'gay person'. It is a cultural identity marker and 'technology of self' one could argue?

"Of course I am mindful I have laid the problem out in categorical and dualistic terms, but this is intentional in order to help understand how you figure the epistemological/ontological basis on which you have arrived at an acceptance of there being such a thing as the 'autistic person' (as opposed to the person who has been diagnosed with autism)."

I prefer the term 'autistic person' as it is used by others to describe my brain, neurology, way of being (lifeworld), cognition, behaviour (actions) etc. Such things are not attached to me, but are pretty central to whatever 'me/I' is to be conceptualised in a way that a medical diagnosis in and of

itself is not (although that is another story too – what is a self anyway etc.?). If one is to reframe such a positioning when one has been so labelled, then I claim it as much as I would other identity markers (e.g. I am a ‘critical theorist’!).

In terms of ‘cognitive theories of autism’ – the one most fitting to my experience would be ‘monotropism/polytropism’ – as that suggests a diversity of potential strategies being employed with regard to attention/interest (and can be applied to any human). Sensory / information processing seems to be central issues for me if one can pin down embodied differences (yet perhaps not anything near adequate categories?). They may not be connection to such ideas at all for someone else diagnosed as ‘autistic’ though. There is some support for EF theory (yet I find it very problematic). As for ToM theory...(grrr...!). Can one generalise to ‘all autistic people’ from this – of course not. Can anyone ‘represent the autistic voice’ – no – not any more than someone can represent the ‘non-autistic voice’. It is a nonsense to suggest as such (as I have reported to some self-advocacy organisations)

Should ‘autism’ as a description be disbanded altogether? Well – it probably will one day, but until that time I think it has some practical usage. ‘Asperger Syndrome’ is no longer in the DSM, but that won’t stop people using the term. Like any identifier it can be used in any number of ways though (to greater or lesser affect perhaps).

It seems to me that a number of ‘autistic scholars’, scientists, critical theorists etc. – all suggest that autism is not a definable ‘natural kind’, but arguing against neurological diversity is another thing, or discussing the potential impact of such diversity (which is like asking the nature vs. nurture question – a bit of a non-starter). If one is to replace autism diagnosis – in practical terms, what does one replace it with? For me, such a discussion should include those most affected by such changes wherever possible.

And so on and so on...

Most social differences get labels, some very derogatory ones, but not all are medicalised. One can be deemed an extravert, lazy, spirited, stupid and so on.

As a teenager I was diagnosed with all sorts, the most striking labels being BPD and Catatonic Schizophrenia. Needless to say, some of my experiences back then put me off psychiatric labelling! My disposition and development were anything but normal though. I have a very high IQ and higher non-verbal IQ, have quite extreme reactions to certain sensory stimuli, am very poorly coordinated, struggle to process more than one thing at a time, so I tend to listen to people rather than look at them when they are talking. Despite my measured IQ, teachers thought of me as a stupid, lazy and underachieving pupil who was deliberately being obstructive. I have had a small number of very strong interests which often turn into large collections to be stored. And so on...

I read more about autism and the differing views. I had never attached the label to myself, as the minimal descriptions I had come across I did not relate to. This changed somewhat though when I read autobiographical accounts. This produced a very powerful sense of recognition and indeed empathy from me, something very rare in my experience. So this led me to look more deeply and thus I started to critique everything that had been said about this description of disposition – as little seemed to be doing a good job of it. When I went for a diagnosis, I was partly at the time doing it as a kind of social experiment, to see if psychiatrists would define me as autistic.

My mother and I gave as accurate answers as we could give, and over the space of a day they came back with a diagnosis of Asperger's. I was proven right in my hypothesis that I would be so labelled in such a situation. When I asked 'are you sure', they replied 'unequivocal on all counts' (interesting when thinking of diagnostic practices to some here perhaps?).

Given the complexity of what we are dealing with, I doubt one will ever find the 'essential autism' at least without changing the meaning of what autism currently is. Which for me is a social construction (or set of very differing accounts) to try and analyse and model such dispositional diversity (in certain perceived traits at least). Such dispositional diversity for me is a given though, we are not identical clones with identical experiences. So on this level, the double empathy problem exists in interactions between anyone to a greater or lesser extent.

Autism is not a clear boundary or category, but in everyday practical terms such dispositional differences are going to be named, and some discriminated against. Even if one used the term dispositionally or neurologically divergent, someone might say 'in what way?'. So, if one is to replace the term autism, and it's various explanations, what is one going to replace it with? How does one explain the above?

It is one thing to say that a term or explanation is not really 'real', it is quite another to come up with a better explanation of such dispositional and experiential diversity – and then practically help people who are being discriminated against largely because of their disposition.

Sami Timimi

I like your answers and it does make me feel that I do indeed need to better educate myself about the critical autism writings you refer to. Perhaps you can suggest or send two or three key papers that you think would help summarise some of the history, theory and practice that you consider important to get across. I think you have done great work to open up spaces for those who wish to identify with the autism construct so that the word can be de-colonised to some degree and develop alternative and less damaging associations and possibilities enveloped in it. But I'm afraid you are still caught in the diagnostic idiom and using the same epistemology as the medics and have not been able to respond to my main issue around the essentialism and universalism. You still cling onto an idea that somewhere medics stumbled on a concept, a fact of nature (rather than culture), that they may have viewed in a negative light, but which has a 'truth' to it. You still talk of autistic people and are arguing that there is something innate/internal/at least partly biological driving the way the 'autistic person' engages with the world. You have your own take on this and talk about 'dispositional' tendencies and then it seems to me get hopelessly lost in trying to define how to understand this, where the boundaries are, how context dependent this is etc. Which is not surprising, because you have stumbled into the epistemological/ontological quagmire of trying to figure out what this abstract concept of autism 'is' and then have to resort to some home spun philosophy untethered from any factual/empirical evidence to 'prove' its existence. You see this is where I think the sort of critique I am involved in takes us properly out of the 'soft left', as I have referred to it, of trying to reconstruct an abstract concept and naming it for what it is – something that does not exist in any concrete form beyond the imagination of those using the concept (whether in deficit or difference forms). Most other service user movements in mental health have been rejecting the excesses of medical model psychiatry for a while and reject the idea that psychiatric diagnoses have validity and many feel trapped by the labeling process. It seems from what you have written you too may have experienced negative labeling being applied to you as a teenager, yet are we to believe that there is something different about 'autism'?

Yes all these other diagnoses (ADHD, schizophrenia, depression) are labels created by a few powerful white men (generally) and that can be seen to lack reliability and validity, but why should autism be different? Well it isn't and you are unable to give me an empirically grounded evidenced argument to support your idea that there is something in the measurable empirical world of brain and biology, because there is nothing you can give. What you are then reduced to is pure interpretive anecdote (e.g. making some rather context depleted comparisons with others you deem 'non' autistic) or personal examples from your own experience. Empirically this proves nothing. This is no different to the countless debates I've had with other medics around diagnosis or effects of medication (for example). When I point out the lack of evidence, biological markers, lack of explanatory capacity, lack of evidence on matching treatment to diagnosis predicting outcomes from treatment etc. they come back with anecdote and their own home spun theories (because the science is missing) – like saying " Oh yes, but I know there is too much diagnosis, but of course there are cases of 'true ADHD' (insert favourite diagnosis here) which we need to diagnose" or despite showing evidence that nearly all anti-depressant effect is placebo "But I know it works I've seen it in the patients I've treated". So anecdote is regularly used when scientific evidence is missing. I'm afraid your responses have convinced me that you have no empirical evidence to back up your idea that there is something empirical 'out there' that exists in you or anyone else that is specifically and characteristically different that equates to 'autism'. If you have evidence other than anecdote, please put this forward. However, don't expect me to believe that you having a diagnosis gives you any special privileges into 'knowing' what autism is any more than doctors making the diagnosis have any special privileges to knowing what autism is. As autism (disease or difference) is conceptualised as hardwired in some way, then until evidence for what this is that is specific and characteristic is forthcoming (and there is no sign of that being consistently found and replicated in either neuroimaging or genetic or indeed any other studies) then the ONLY scientific conclusion you can come to is AUTISM DOES NOT EXIST as biological fact – it exists as a cultural fact. One of the reasons I think many of us feel the need to speak out about this, is that a lack of acknowledgement that autism is a construct leads, as with other diagnoses in psychiatry, to reification – a mistaking of a humanly made ideas for concrete reality (I don't have time to go into the full ramifications this can have on people's lives, some of which I suspect you experienced with other labels when you were a teenager). Autism is a 'brand'. Neoliberal values encourages individuals to compete with each other resulting in 'winners' and 'losers', and where the ever present anxiety of losing has been subject to market forces resulting in the growth of a profitable mental health industry that locates causes and solutions of perceived 'failure' and other struggles as residing within the individual. Autism is sold like other diagnoses with promises and whilst its popular right now (we have so many parents and teachers locally wanting children assessed for 'autism' – whilst learning difficulties has very little value as a brand, so I can't remember the last time someone asked for their kid to be assessed for learning difficulties), dangers lurk, not just in the effects of internal stigma and labeling, but its 'desirable' status may change – for example, we are increasingly straying into 'anti-social personality disorder' territory with professionals arguing that many criminals in fact have 'autism'. If it gets conflated with 'dangerousness' beware.

Damian Milton:

There you go again – putting words in my mouth and making assumptions – please use more of the strategy of asking questions – less stressful.

"But I'm afraid you are still caught in the diagnostic idiom and using the same epistemology as the medics and have not been able to respond to my main issue around the essentialism and universalism."

I am certainly not using the same epistemology as the medics in the slightest – get that please (indeed – it would seem to me that you are the one arguing from an empiricist / positivist argument alone!?!).

The ‘essential difference’ of autism? As you know, nobody has the answer to that and it looks increasingly likely nobody ever will. It has always been diagnosed on the medic’s view of expressed behaviour etc. – thus autism never has been a natural kind referring to an essential difference. Many psychological theories have been proposed but all lack full explanatory value. So – on this front I am much more in line with your way of thinking than you would give me credit for – and that repeated mistake is getting quite annoying!

“You still cling onto an idea that somewhere medics stumbled on a concept, a fact of nature (rather than culture)..”

Wrong!

“...that they may have viewed in a negative light...”

Yes – those deemed autistic by the medical profession are seen within a deficit normative model that I would not at all personally adhere to.

“You still talk of autistic people...”

As a cultural entity (as well as talking of embodied dispositional diversity).

“...and are arguing that there is something innate/internal/at least partly biological driving the way the ‘autistic person’ engages with the world.”

Yep – as I would all human beings – what the ‘cut off’ boundary is – as I have said is down to social convention and the perception of the one doing the cutting.

“You have your own take on this and talk about ‘dispositional’ tendencies and then it seems to me get hopelessly lost in trying to define how to understand this...”

No more lost than any other when discussing the ‘nature vs nurture’ debate – I just state it as an unanswerable question to ponder possibilities about – rather than stating a conclusion one has no evidence for.

“...where the boundaries are...”

Are entirely down to social convention – see my quote from 1999

“...how context dependent this is etc.”

Very – all use of language is – no?

“Which is not surprising, because you have stumbled into the epistemological/ontological quagmire of trying to figure out what this abstract concept of autism ‘is’...”

A contested social construct regarding people so labelled.

“...and then have to resort to some home spun philosophy untethered from any factual/empirical evidence to ‘prove’ its existence.”

I am not trying to prove autism as an essential natural kind definable biological entity. What I do see as biological/dispositional/social reality is diversity which is then talked about, categorised and labelled by people.

A side point – empirical work directly looking at monotropism has never been funded to my knowledge (although even Lovaas of all people talked about a similar phenomena, albeit from a highly pathologising narrative).

“You see this is where I think the sort of critique...”

Which keeps missing the point entirely it would seem.

“...are involved in takes us properly out of the ‘soft left’...”

I really don’t agree with you – it would seem to me that you are arguing for some kind of positivist essentialist truism or that a label should be abandoned – would you do the same for gay people or punks? It seems to me your epistemology is one that is in line with positivism and science (not that I am against such work where appropriate for what is being studied) – I will let others decide who they think the ‘soft left’ is here in this discussion.

“...something that does not exist in any concrete form beyond the imagination of those using the concept (whether in deficit or difference forms).”

If you are talking about ‘autism’ – ‘autistic people’ said this long before any of you in this group did (Larry Arnold, 2004 as an example).

If you are talking about the neurodiversity of people – I think you are talking obvious nonsense.

“Most other service user movements in mental health have been rejecting the excesses of medical model psychiatry for a while and reject the idea that psychiatric diagnoses have validity and many feel trapped by the labelling process.”

Yep – I have been one for many years – perhaps you would like to look up the ‘Mad Studies and Neurodiversity Symposium archive’ as a starting point?

“It seems from what you have written you too may have experienced negative labelling being applied to you as a teenager, yet are we to believe that there is something different about ‘autism’?”

In the way the culture had developed and various members express themselves – yes.

“Yes all these other diagnoses (ADHD, schizophrenia, depression) are labels created by a few powerful white men (generally) and that can be seen to lack reliability and validity, but why should autism be different?”

In that respect, it isn’t.

“Well it isn’t and you are unable to give me an empirically grounded evidenced argument to support your idea that there is something in the measurable empirical world of brain and biology, because there is nothing you can give.”

In terms of ‘autism’ this is not what I am arguing – in terms of neurodiversity – look at any collection of brain scans, or talk to people!?!

“What you are then reduced to is pure interpretive anecdote (e.g. making some rather context depleted comparisons with others you deem ‘non’ autistic) or personal examples from your own experience. Empirically this proves nothing.”

I wasn’t trying to prove anything empirically with them – merely exploring the practical use of the term in context. You have often stated that the label can have a negative effect on those so-labelled, not once have I seen you talk about perceived positives (whatever you and I may make think of these). So – who is that is missing out evidence that is contrary to their arguments? Maybe you can say why it is you concentrate solely on the negative in this respect?

Also – do you think ‘situational knowledge’ is a waste of time? Who is being patriarchal there then?

“...Oh yes, but I know there is too much diagnosis, but of course there are cases of ‘true ADHD’ (insert favourite diagnosis here) which we need to diagnose” or despite showing evidence that nearly all anti-depressant effect is placebo “But I know it works I’ve seen it in the patients I’ve treated”. So anecdote is regularly used when scientific evidence is missing.”

You are ranting here – I was not trying to use anecdote as evidence of biological difference.

“I’m afraid your responses have convinced me that you have no empirical evidence to back up your idea that there is something empirical ‘out there’ that exists in you or anyone else that is specifically and characteristically different that equates to ‘autism’.”

I haven’t tried and wouldn’t wish to.

“However, don’t expect me to believe that you having a diagnosis gives you any special privileges into ‘knowing’ what autism is any more than doctors making the diagnosis have any special privileges to knowing what autism is.”

Well – other than embodying a disposition so-labelled (at least culturally), being an active sociologist in the field, being an active member of autistic communities and culture – all of which gives me (I feel) a greater ‘interactional expertise’ with said cultures (I say this with confidence given your repeated misrepresentations, overgeneralisations and simplifications). Using the idea that those so labelled cannot give an explanation empirically as to what it is (when scientists cannot) as a way of dismissing what is said by them is to me a bit bizarre and unethical. Collins and Evans (2007) argue that ‘interactional expertise’ could be seen as a minimum standard for studying cultural groups – I would say this is something you show no evidence of. I would also say that those with ‘contributory expertise’ within such cultures are of value when talking about said cultures and the variety of viewpoints that exist therein.

“As autism (disease or difference) is conceptualised as hardwired in some way...”

Well it is used as I have said before to describe one’s neurology, cognition, way of being, behaviour etc. by medics and so on.

A brain and subjectivity develop over time. Do you deny (as people) we have differing (yet developing and non-static) brains? Differing ways of being in the world? Differing experiences? And that some whether willingly or not are ascribed a status of ‘autism’ as a descriptor of said perceived differences (in any of the above mentioned)? Whether or not ‘autism’ is an empirically justified category or not is immaterial it would seem to such ascriptions being made (and experiences of being so labelled being different to not being so – and a multitude of other experiences associated with being seen as an ‘outsider’ for one’s disposition and way of being in the world – however one wants to describe it oneself).

“...then until evidence for what this is that is specific and characteristic is forthcoming (and there is no sign of that being consistently found and replicated in either neuroimaging or genetic or indeed any other studies) then the ONLY scientific conclusion you can come to is AUTISM DOES NOT EXIST as biological fact – it exists as a cultural fact.”

Quite so – the same studies show neurodiversity to be a ‘fact’ in your view – or not?

“One of the reasons I think many of us feel the need to speak out about this, is that a lack of acknowledgement that autism is a construct leads, as with other diagnoses in psychiatry, to reification – a mistaking of a humanly made ideas for concrete reality (I don’t have time to go into the full ramifications this can have on people’s lives, some of which I suspect you experienced with other labels when you were a teenager).”

The term ‘teaching your grandmother to suck eggs’ springs to mind. I do not need a lesson in reification.

“Autism is a ‘brand’.”

Or several competing?

“Neoliberal values encourages individuals to compete with each other resulting in ‘winners’ and ‘losers’, and where the ever present anxiety of losing has been subject to market forces resulting in

the growth of a profitable mental health industry that locates causes and solutions of perceived 'failure' and other struggles as residing within the individual."

Again – 'teaching grandmother'.

"...dangers lurk..."

And yet, you have yet to address my question (originally first asked to you in 2012) about what you would replace diagnosis with and what the practical ramifications of that would be – or would you deny any neurological / dispositional differences between people? And so – no need for a replacement? It is not very radical (nor ethical) to me to propose we disband the label without having some kind of idea about 'what next'.

"...with professionals arguing that many criminals in fact have 'autism'. If it gets conflated with 'dangerousness' beware."

Lol – I think that happened a long time ago!?!

"Perhaps you can suggest or send two or three key papers that you think would help summarise some of the history, theory and practice that you consider important to get across."

Well – I don't think the below really summarise, but may give you a taste of what is available?

<https://madstudies2014.wordpress.com/archive/mad-studies-neurodiversity-symposium-archive/>

<http://www.autscape.org/2015/programme/handouts/Autistic-Culture-07-Oct-1999.pdf>
(old article, his views have of course changed a lot since)

<http://shopfront.chester.ac.uk/images/normalcy/stevengraby.pdf>

<http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/AR2/html>

<http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/AR10/html>

<http://www.autscape.org/2016/programme/presentations>

<http://dsq-sds.org/article/view/3876/3405>

<http://shura.shu.ac.uk/7164/>

I know it is different, but what evidence can you show me of an essential difference of 'being gay'? I guess not a great deal that is fully explanatory at least! So, if this is nothing but a cultural categorisation, should we disband the term because someone who doesn't so identify thinks so? Should 'autism' be disbanded as a diagnostic category? Perhaps so? But then, what would you

'diagnose' and how would people acquire services and support from that model? Or do you think people don't need anything but the same as everyone else? Universal Design in all things? How would you like to practically bring that about? And how will that help the well-being and life chances of 'autistic people' when that change occurs? Saying autism is a myth, but giving no alternative explanation for dispositional differences and experiences and discrimination – nor practical strategies and ideas – is ill-conceived and potentially damaging.

So – what is your plan as to what we should change to?

Sami Timimi

I do want to reiterate that I have found your replies interesting and informative. I admire your tenacity and willingness to engage in this discussion and I like your 'pulling no punches' approach. You have important things to say and as I said in my last email I believe that your work and those of colleagues from the critical autism movement aligned with your understanding has been extremely important in opening up new and creative spaces for those labelled autistic and their supporters. I do want to educate myself further on these perspectives and am grateful to the links you've sent me and will get round to looking at them further. I do also understand that many people have positive experiences of being labelled, whether it's a parents struggling with a sense that their child's struggles are because they are a 'bad parent' or someone trying to make sense of why they are struggling/suffering. I understand there are many psychological functions of labeling from validation, understanding, promise of change and so on. However, in terms of autism the potential negative effects have hardly been mentioned in available discourses hence our small attempt to give such a perspective an airing, grounded in the knowledge that autism as a label in our current state of knowledge can have no explanatory capacity.

I think we have much ground in common and I like the concept of autistic/neurodivergent cultures and the understanding of the culturally constructed nature of the spaces created by this. There does remain an important difference. I will try and make a final attempt at articulating this difference in hopefully a more respectful manner than my last email.

Let me if I may take a few direct quotes from your previous answers:

[autistic people as] ..."embodied dispositional diversity", agree with my statement that you are arguing "that there is something innate/internal/at least partly biological driving the way the autistic person engages with the world", "What I do see as biological/dispositional/social reality", "Differing ways of being in the world", "embodying a disposition so-labelled" etc. You then give an account of how you connected with autobiographical accounts, but had to rely on a medical process to confirm that you had a similar diagnosis to those biographical accounts.

So if I can attempt to summarise what comes across to me from this account is a concept that there is a 'dispositional' tendency in people that is driven from within and that accounts (i.e. has explanatory capacity) for differences in the way (for example) you interact with the world. You also tacitly acknowledge that this dispositional tendency has been first introduced to us via the medical community naming certain tendencies as 'autism' and I am guessing that at present in order to have entry into the 'autism' communities you first need the medical community to make the diagnosis. I understand you disagree with what they then do with this diagnosis, but it is still these people who have adopted the role of 'expert' in diagnosis that are needed in order to signify entry (unless, perhaps, you believe that there should be self-diagnosis, although you do state "There are of course issues with 'self-diagnosis'").

There is a point of departure between us and I think there is an epistemological issue here, although and I am not stating that this is the totality of what can be said about embodied difference. To arrive at a notion that there is an innate/biological disposition that has a certain specificity (currently requiring doctors to identify that) and has explanatory capability for one's behaviours regardless of

context, then the most relevant epistemological framework to confirm or refute that is the positivist, empirical, scientific one. You have put forward a hypothesis concerning causality and this needs to be tested. In science, we always start with the null hypothesis – we assume no link or causality until it can be proven that this assumption must be incorrect. This is where I believe the argument that there is a biological/innate basis is struggling to be made. The null hypothesis currently stands – there is no innate characteristic discover-able, biological ‘substrate’ that coincides with those diagnosed with ‘autism’ (or to use your concept – having those dispositional tendencies) and can explain the way their ‘being in the world’ manifests. To talk about us having different brains doesn’t add anything to the argument and is as unhelpful to unpacking this as saying all behaviours are ultimately down to genes (which of course they are). So my epistemic point here is that the most relevant framework for establishing the idea that those who belong to the autism communities have a biologically/neurologically based disposition, which causes them to interact differently with the world – is the scientific, materialist, positivist one – as that is how we establish biological facts. As there is insufficient evidence to support the null hypothesis as being incorrect, then there is no biological basis for what currently doctors diagnose as autism. But it exists in our discourses; therefore it exists as a fact of culture, and not as a fact of nature. This means I am right there with you when you explore the cultural aspects of what you call autism communities, but I diverge, when you start ascribing ‘dispositional’ qualities with explanatory capacities.

It should be fairly straightforward from this to understand why I don’t share your idea that autism cultures/communities can be straightforwardly compared to gay or punk communities. The latter referred to are more easily self-identified (sexual preference or music preference, which then develop various cultures e.g. around dress or lifestyle), do not need to posit a biological disposition (whether there is or not), do not need a doctor to identify and allow potential entry into the communities etc. Of course there are some similarities too (dealing with stigma, emancipation, gaining comradeship etc.) that sit in the realm of social and cultural life.

You also asked what to use instead if not autism. The problems associated with seeing people through the ‘prism’ of autism was my initial driver to writing about this in a world of expanding numbers being diagnosed. As you know the ‘Myth of Autism’ book I co-wrote with Neil and Brian looked at the drawbacks and their experiences as two people diagnosed with an ASD were not as positive as yours about the diagnosis. Two immediate problems: two tier services – where children diagnosed with autism get a service (such as autism outreach to schools) whereas others who don’t get the diagnosis, but could equally benefit from such services (e.g. diagnosed with the increasingly unpopular label LD) don’t. Secondly, the opposite can happen, where someone is denied a service (e.g. presenting with anxiety around other kids) because they have a diagnosis of autism and therefore they are told it is part of their autism and there is nothing we can do about it or the service doesn’t deal with those diagnosed with autism or a practitioner imagines they don’t have the ‘expertise’ to deal with autism etc. Autism, like any label, can obscure the particular challenges, dreams, strengths, skills, lack of certain skills, problems, resources etc. of any person. What diagnostic based practice leads to is a focus on process (because they ‘have’ autism, we must follow this or that ‘pathway’) even though the evidence on outcomes has not found any specific ‘treatments’ that differentially improve outcomes for those diagnosed with autism compared to those who are not and are at a similar level of functioning. Also diagnostic based practice leads to a focus on ‘symptoms’ (i.e. in autism’s case behaviours). You will I, expect, have similar critiques to me on these aspects. My practice focuses on outcomes (whether from the perspective of those I’m working with things are improving or not) and here diagnostic discussions can be put to one side and hardly ever feature. Different people have different ideas about what they would like to change or understand. From working to improve relationships to skills for managing anxiety, to helping parents understand emotional dynamics – every person diagnosed or not has a different tale to tell, context to live, and change they wish to achieve. People don’t get stuck with long term treatments or invited to a deficit view – the idea of difference that you rightly promote is something I regularly use, and probably take a bit further stressing that though we have various similarities that can bind us

(interests, music, family whatever), each one of us is ultimately unique and how wonderful is that, knowing that there is absolutely no one else anywhere in the world who is exactly the same as you. I have no problem with people using a shorthand of 'autism', just ask that it is kept in mind that this is used as a strategy to manage a situation no more, no less.

OK. Hopefully I haven't been too 'ranty' this time, but it's me signing off from this particular debate

Damian Milton:

"You then give an account of how you connected with autobiographical accounts, but had to rely on a medical process to confirm that you had a similar diagnosis to those biographical accounts."

Nonsense – I realised the similarity in accounts (or not) when I read them, I was diagnosed five years later – as I said, I partly went through the process as a social experiment to see what psychiatrists would do and how they would define me (I had already accepted that I was 'somewhere on the autism spectrum' as a personal construct – not biological factual reality or static innate 'disposition'). This had no effect on my sense of selfhood, but did give me a social status I did not have before (and one which I could continue to contest – similar to other ascriptions whether medicalised or not).

"You also tacitly acknowledge that this dispositional tendency has been first introduced to us via the medical community naming certain tendencies as 'autism'..."

Erm...nope...dispositional diversity is part of human diversity and so would be as old as human beings are imv. Before I was labelled autistic, I was labelled lazy, stupid, underachiever, BPD, catatonic schizophrenic – I also attracted such nicknames as 'Frankenstein' and 'Herman' and 'Bolts' at school due to the way other children perceived me. This has nothing to do with how a medical professional names someone's dispositional state. If one looks at the work of Mitzi Waltz, one can see characterisations historically (and in fiction) of what we might call 'autistic' by today's naming of dispositional characteristics. The term 'autism' was first used in a clinical setting by clinicians. Calling oneself an autistic person – is not in order to reify such assertions – much like a feminist may try to reclaim terms that have been used in derogatory ways – one strategy is to reframe the discussion around dispositional diversity and what it is like subjectively for those diagnosed as 'autistic' and so on.

"...and I am guessing that at present in order to have entry into the 'autism' communities you first need the medical community to make the diagnosis."

You would be guessing completely wrong – such a simple mistake as this shows why I think you lack the interactional expertise to be writing about the views espoused within said cultures.

"I understand you disagree with what they then do with this diagnosis, but it is still these people who have adopted the role of 'expert' in diagnosis that are needed in order to signify entry (unless, perhaps, you believe that there should be self-diagnosis, although you do state "There are of course issues with 'self-diagnosis'")."

Both have difficulties with them – quite obviously I think. Autistic communities tend to be inclusive of those who are diagnosed, those who self-diagnose, and those who do not identify but are simply interested for whatever reason. Some groups are more exclusive – as the culture is not one static

singular entity (as cultures aren't – not to me anyway) – I would not be interested personally in any group that required a medical diagnosis for entry.

“To arrive at a notion that there is an innate/biological disposition that has a certain specificity (currently requiring doctors to identify that) and has explanatory capability for one's behaviours regardless of context, then the most relevant epistemological framework to confirm or refute that is the positivist, empirical, scientific one.”

I am not arguing that there is an innate/biological disposition (see responses elsewhere), nor one with any specificity – it is 'social conventions' which name such things, whether very specific or not – 'the autism spectrum' is an umbrella term. As a (medicalised) scientific concept explaining behaviours regardless of context, I think this is nonsense (see previous comments again). Common dispositional tendencies within, without or across categorical boundaries could be operationalised and measured, but generally these have been ill-conceived imv with regard to what people call 'autism'. Both monotropism type ideas and sensory processing differences were jettisoned early-on as specific and explanatory of what was thought of as 'autism' (although EF issues, ToM issues etc. as operationalised in studies are not specific and explanatory either, but never mind...). One of the problems is what empirical studies are funded and what they are testing for. Still, by working back from a 'behaviourally' defined diagnosis, one is unlikely to find one easily identifiable common cause.

In 'autism' this for me is like looking for the 'Holy Grail' (and yes I do like Monty Python).

“You have put forward a hypothesis concerning causality...”

Of 'autism' – no. I have said that monotropism is a common tendency I've experienced amongst those labelled autistic. Well – that would depend on how one conceives it perhaps? It does a good job of hypothesising possible consequences of a highly monotropic use of attention which would perhaps influence some of the dispositional tendencies people may experience – I find it a useful model for certain things personally. I would like to see more empirical studies in this area, but some have wanted that for a long time.

“...and this needs to be tested.”

Well – Liz Sheppard's team and their experiments were conducted without any knowledge of my theories regarding the 'double empathy problem', yet would seem to be supportive of such a model. But like monotropism, I would like to see it tested more – anyone fancy funding it?

“In science, we always start with the null hypothesis – we assume no link or causality until it can be proven that this assumption must be incorrect.”

I first read Karl Popper's work in the early 90s.

“This is where I believe the argument that there is a biological/innate basis is struggling to be made.”

No kidding (see 'Holy Grail' comment earlier)! You were not the first to point this out though – see Larry Arnold's essay (which originates from a course he did circa 2004).

“The null hypothesis currently stands – there is no innate characteristic discover-able, biological ‘substrate’ that coincides with those diagnosed with ‘autism’ (or to use your concept – having those dispositional tendencies) and can explain the way their ‘being in the world’ manifests.”

Nope – and given the complexity of what is placed within this umbrella term, I very much doubt anyone ever will. I am also not an eliminative materialist when it comes to philosophy of mind, so I don’t think ‘dispositional tendencies’ will ever be fully explained. We can scrap the DSM etc. – but what then for the people who depend on the practical supports and benefits a label (sometimes) helps to provide? Perhaps you would like to tackle this pragmatic issue in some way? Would be nice to know more of what you think about this (I guess I will just keep asking...).

“To talk about us having different brains doesn’t add anything to the argument and is as unhelpful to unpacking this as saying all behaviours are ultimately down to genes (which of course they are).”

I think it does, as does many within the ‘neurodiversity movement’ one could say.

“So my epistemic point here is that the most relevant framework for establishing the idea that those who belong to the autism communities have a biologically / neurologically based disposition, which causes them to interact differently with the world – is the scientific, materialist, positivist one – as that is how we establish biological facts.”

And autism isn’t one imv – or in the view of scientists like Eric London, Chris Gillberg, etc. it would seem to me. How is what you are offering different?

“As there is insufficient evidence to support the null hypothesis as being incorrect, then there is no biological basis for what currently doctors diagnose as autism.”

Nope.

“But it exists in our discourses; therefore it exists as a fact of culture, and not as a fact of nature.”

Yes, but dispositional diversity and the consequences of it are of course influenced by nature, and how we decide to categorise such diversity is social construction – as Larry Arnold said many years ago: ‘shifting goalposts’.

“This means I am right there with you when you explore the cultural aspects of what you call autism communities, but I diverge, when you start ascribing ‘dispositional’ qualities with explanatory capacities.”

Dispositional qualities being described do not have explanatory capacity in empirical scientific terms – no. Are they of importance – well, they are to me. Can they be tested better – I think so.

“It should be fairly straightforward from this to understand why I don’t share your idea that autism cultures/communities can be straightforwardly compared to gay or punk communities. The latter refer to are more easily self-identified (sexual preference or music preference, which then develop various cultures e.g. around dress or lifestyle), do not need to posit a biological disposition (whether

there is or not), do not need a doctor to identify and allow potential entry into the communities etc. Of course there are some similarities too (dealing with stigma, emancipation, gaining comradeship etc.) that sit in the realm of social and cultural life.”

There are many similarities – which is why I raised it. Of course there are differences too. Yet, this community does not need to posit a static biologically explainable disposition – and generally the view being most often expressed is that of neurological diversity having an impact on social lifeworld (+disposition or what have you). A doctor is not ‘needed’ as such to experience what one experiences or how one chooses to identify whatsoever (yet I accept the tensions the history and terminology of course bring to the community) – and this is certainly not needed for entry into the community (as said before in this response).

“You also asked what to use instead if not autism. How you might approach a situation differently without a label.”

And I said how such options are not always open to me – and sometimes I need a short-hand term.

“The problems associated with seeing people through the ‘prism’ of autism was my initial driver to writing about this in a world of expanding numbers being diagnosed. As you know the ‘Myth of Autism’ book I co-wrote with Neil and Brian looked at the drawbacks and their experiences as two people diagnosed with an ASD were not as positive as yours about the diagnosis.”

Yep – but your book is thus as skewed as one that concentrated on only the positives (in this regard) – yes I can see you were trying to rebalance the discourse, but one would have to read more widely to get a fuller picture. So – for me it came across as potentially you choosing experiences / co-producers to fit your argument (although that is a common human ‘trait’ perhaps?).

“Two immediate problems: two tier services – where children diagnosed with autism get a service (such as autism outreach to schools) whereas others who don’t get the diagnosis, but could equally benefit from such services (e.g. diagnosed with the increasingly unpopular label LD) don’t.”

Such as? My diagnosis of Asperger’s has not led to anything but a small bit of help once from the DSA. I think this is too simplistic. Also – many services for autistic people shall I say are ‘counterproductive’ (or much worse).

“Secondly, the opposite can happen, where someone is denied a service (e.g. presenting with anxiety around other kids) because they have a diagnosis of autism and therefore they are told it is part of their autism and there is nothing we can do about it or the service doesn’t deal with those diagnosed with autism or a practitioner imagines they don’t have the ‘expertise’ to deal with autism etc.”

Well – often they don’t have sufficient expertise imv. Saying something is ‘part of their autism’ as if separate to the individual in some way is to me an ontological error, as autism is a description of said person’s ‘disposition’ and their actions and not a ‘biological fact’ as you point out. When a service says they can’t help people – then I suggest gaining more expertise in the lived experiences of said group – or stop excluding people etc. Yes – ‘autism’ can be used to exclude, but one doesn’t need a label of autism to be excluded due to people’s perceptions and reactions to one’s ‘disposition’.

“Autism, like any label, can obscure the particular challenges, dreams, strengths, skills, lack of certain skills, problems, resources etc. of any person.”

For me, that would depend somewhat on the meanings one attaches to the label. It doesn't have this effect for me in my own personal constructs – may do if I use the term in certain social situations. At times useful, sometimes not so – a linguistic / social 'technology of self' or some such?

“What diagnostic based practice leads to is a focus on process (because they 'have' autism, we must follow this or that 'pathway')...”

Yes – but I argue against the use of the term 'has autism' or such one-size-fits-all practices in regard to people, autistic or not.

“...even though the evidence on outcomes has not found any specific 'treatments' that differentially improve outcomes...”

Often defined as reducing deficits / normalisation of dispositional differences from the idealised norm – and not something that I would agree with the argument for – but yes, evidence of these outcomes of specific 'treatments' is shoddy to say the least. I have written about this too (in various ways in various articles).

“...for those diagnosed with autism compared to those who are not and are at a similar level of functioning.”

Seeing as there is not at all good evidence for medical interventions with autistic people – as you say – so what? Says nothing about 'autistic people' who have 'spiky profiles' of abilities and who are not classically 'LD/ID' either.

“Also diagnostic based practice leads to a focus on 'symptoms' (i.e. in autism's case behaviours). You will I, expect, have similar critiques to me on these aspects. My practice focuses on outcomes (whether from the perspective of those I'm working with things are improving or not) and here diagnostic discussions can be put to one side and hardly ever feature.”

Really – not feature? Why not? What would you advise for someone who already has a diagnosis and is worried about when they get their PIP brown envelope through the door and their benefits being possibly cut? That their diagnosis is not based on biological fact? How is this going to help them?

Sami Timimi:

Appreciate your responses and suggested readings, which I have found interesting and useful, but you have not convinced me about utility or validity of your version of socially constructed nature of autism/neurodivergence debate, nor do I feel you have addressed my points properly. Reading some of the authors you pointed me to, further confirmed my 'bias'. Like you I argue (and wrote about years ago) that the nature v nurture debate is pointless, unnecessary, and unhelpful. However, I don't think, despite your protestations, you can escape that the concepts you and your critical colleagues use (autism, neurodivergence, disposition, mono tropism etc.) have more than just

descriptive function and in the way they are being used are meant to have a 'explanatory' purpose (that 'autism' explains something about a person's diagnosed/identified with autism's behaviour). This is particularly true of some of the other writers you referred to: e.g. Steven Graby "There is a spectrum of neurological difference – I see this as incontestable" or Larry Arnold "Brain scanning and other research has borne out that we look at people differently and tend to use the same parts of the brain to process people as NTs use for objects". Just the word 'neuro' points to where the assumption lies about what is driving differences (at least in part – and in the above statements in large part).

So can we at least agree that we diverge in our view about autism having any explanatory capacity that is (at least in part) driven by 'neurology' (I don't agree with either of those positions obviously)? I also see that you are struggling with the same problems of description/caseness that the medics struggle with and haven't properly addressed. You managed a reasonable deconstruction of the problems involved in personality type and trait theories propounded by, for example, Eysenck, in a 2014 paper of yours in 'autonomy', but seem to have a blind spot when it comes to applying the same critique to concepts of autism (reminds me of Michael Rutter, who does a reasonable job of pointing out problems with diagnostic concepts lacking a 'marker' or some sort of anchor, such as dyslexia, but has a blind spot when applying the same standards to autism). You are unable to sufficiently address the problem of heterogeneity (that bedevils medical definitions), so what you end up with is a vague, difficult to pin down (or even understand) of "Autistic people could be said to exhibit a dynamic quality of perception, one less stratified by learnt schemas, one less socialised into obeying normative ideologies, but an embodied sociality nonetheless" – try operationalising that! I think you obfuscate this problem by referring to philosophers like Merleau-Ponty and their concepts of embodiment in a way that was not used by him. What this then leads to is an idea, again similar to medics, that it is only someone who has 'expertise' in autism who can have the relevant knowledge of what autism 'is' and thus how to recognise and deal with it, such as in your email you say "When a service says they can't help people – then I suggest gaining more expertise in the lived experiences of said group". So you just have a different idea of who has the authority to be granted an 'expert' status'. I see being an expert in autism as an oxymoron. So can we agree that we diverge on our views as to whether autism describes anything specific or characteristic?

For me the problem remains that the neurodivergent view of autism is the opposite side of the same coin that the 'disorder' view of autism represents. Like all other diagnoses made in psychiatry (apart from the dementias though there are some problems here too), there are the similar problems of explanatory capacity and descriptive specificity. Thus the neurodivergent view has been easy to usurp into current practice as it upholds the idea that there is a 'thing' out there that can be recognised and is called 'autism', and as a result the 'difference' view is now often covered in mainstream literature. I think it has contributed to the lack of critique on the rapid expansion of the numbers being diagnosed with autism, which shows little signs of slowing down. This is why I think the critical autism we are involved in is different to the one you are involved in. You are critiquing the medical view; many of us are critiquing the whole lot including your positions.

Damian Milton:

It seems that you are still missing the point. So again, I will try and explain...

Most of the concepts I have referred to are being used descriptively, particularly 'autism'.

Monotropism is offered as a model of differing attention/interest strategies being used cognitively. Dinah Murray (and some others) argue that those that have a tendency toward a monotropic attention strategy are often deemed / described as autistic.

Disposition is being used as I described before. Neurodivergent is more of a social category (as neurotypical is also a social construct based on embodied diversity).

The quote you use of Steve Graby does not refer to Autism, but the idea that neurological diversity is a brute fact. Something I would agree with. Diversity in neurological development will impact on perceptions and experiences of the social lifeworld, whether labelled 'autistic' or not. The quote you use from Larry is now an old one and I am sure his position will likely have changed on this. However, the best people to ask would be Steve and Larry – which is why I struggle to see why one would not wish to invite them to such a gathering of people to discuss such issues.

I do not think autism as a medical / biological category has explanatory value, or the dominant cognitive theories of autism.

I do not see autism in terms of a set of definable traits – and I apply the same critique of trait theory to autism trait theory (such as the work of Baron-Cohen).

What I suggest regarding dynamic quality and the use of schemas has and is being studied in various ways and has resulted in a number of contested arguments between cognitive scientists. There was a paper some time ago now on 'hypo-priors' as a theory. So very hard to operationalise and research, but not impossible, and I hope to see some directed research in certain areas of cognition in future. I very much doubt there will ever be anything that is explanatory of all that are currently labelled autistic though, as I have said previously, this is like looking for the Holy Grail – it most likely does not exist. So it does not describe anything specific – unless used in a cultural context.

As I have said before, autistic culture exists and one can gain expertise in that. There is also expertise in the lived experience of those so labelled (much like in Mad Studies). There are other forms of expertise applied to the culture of autism. What you have consistently shown me is that you lack is interactional expertise with autistic culture – and it is infuriating that you continue to misrepresent it, whilst not letting said people speak for themselves, either in the book, or it would seem this event.

What you are critiquing as the 'difference model' is not my view, but a simplistic mischaracterisation and straw man argument. What you call 'critical autism studies' – I see as a misuse of the term. Criticising the scientific literature on autism and saying that autism is not a definable natural kind is nothing new.

So – rather than interrogating my position – can we interrogate yours?

If autism is a myth, what explanation do you have for the lived experiences reported, for 'stimming', for not perceiving past or future (for a particular case study) – and so on? An individual profile? How will this work in practice?

It is one thing to say that the models others use lack explanatory value; it is something else to try and explain what is going on. So – do you think neurological diversity is a myth? Do you think that this has no impact on lived experience and development? Do you not think that people who are 'neuro' divergent are not discriminated against? Do you think we have nothing to learn about such experiences from the people experiencing them?

What is your explanation and practice model?

Sami Timimi:

We are indeed going round in circles. You seem intent on labeling me as 'misrepresenting' you. I do not believe I am. I understand your reference to autistic culture as 'existing' as being a social construct with many facets that is useful for many people so labelled or not (such as having a personal empathy/connection with said cultures). As I have repeatedly said I have found some of your explanations helpful, informative and enriching and I will certainly be making greater use of these insights in my own clinical practice. But, I remain unconvinced that you have addressed some essential problems I have with your on-going confused definitions and embedded idea of explanatory value, which I believe leads to some similarities with the problems from medical definitions (DSM remember is meant to be descriptive with no assumptions about cause – but it just keeps creeping in). I can't help feeling you want to bake your cake and eat it! In your latest email you say (for example) "Most of the concepts I have referred to are being used descriptively, particularly 'autism'" and "Neurodivergent is more of a social category" and then start using them as potential explanatory vehicles (but of your own theory), for example, "What I suggest regarding dynamic quality and the use of schemas has and is being studied in various ways and has resulted in a number of contested arguments between cognitive scientists. There was a paper some time ago now on 'hypo-priors' as a theory. So very hard to operationalise and research, but not impossible, and I hope to see some directed research in certain areas of cognition in future". You can't help but get drawn into this and have repeatedly done so and then denied you've done it! The quotes from other authors were only one of many and they were directly from the papers you pointed me in the direction of, which I subsequently read, with the Larry Arnold quote coming from a publication in *Autonomy* in 2012.

With regards descriptive utility/specificity, again you haven't been able to address the question of heterogeneity and lack of specificity, leading you to effectively invent your own version of what 'autism' is and you can then avoid these more empirical questions by the get out clause of its a social construct. However, you also guard entry into this by self-defining who has the right to be seen as 'expert' by talking about those with lived experience – and so you neatly avoid the problem of those with lived experience of 'what'? The reason you continue to avoid dealing with these more empirical questions is that you can't and so you won't. Fair enough, but let's at least acknowledge that this is a point of divergence between the sort of critical autism I'm engaged with and you are. I am not trying to suggest that one is better than the other, just that they have some important differences in focus – and the focus I and colleagues are engaged with is just as legitimate as yours.

In terms of what to do instead, this is the reason I personally critique autism and all other mental health/psychological diagnoses. Unlike most of my colleagues I monitor outcomes using a brief patient and/or parent rated outcome measure (Outcome Rating Scale) so I keep a focus on whether what we are doing together is leading the people I see to record improvements (from their perspective, by whatever is important to them) and I therefore have an on-going record of their outcomes. Unlike the outcome literature on outcomes in standard mental health services and some national surveys, which finds as few as 8% of patients seen by CAMHS services in some areas experience significant improvements, my personal outcomes run at around 70-80% of my cases, which is similar to that found in research and also means that most of the people I see improve by their own perception and get discharged. I do that primarily by NOT focusing on diagnosis (I've attached a couple of 'magaziney' articles I wrote about that way of working in case you're interested).

I also think it's ludicrous to accuse me or any others in this group of "not letting said people speak for themselves". You have been perfectly happy to express your opinions, nobody has stopped you, and the critical autism you represent has received wide coverage (as it should). What the RAN want to do is create some space for this other and more far reaching critique of all aspects of the concept to be made. In terms of 'said people' of course there is some who have a personal background with 'lived experience'. You do not have monopoly over this area.

I think it would help this discussion if you could at least acknowledge that there are some differences in what we are examining.

Damian Milton:

Rather than taking on all of your points now, I will just try and clarify a few.

Whilst I think Autism is an umbrella term and not biological fact, I think embodied diversity including neurological / developmental differences do exist and impact on the experiences anyone has. Some of these phenomena tend to be more common imv within the population labelled autistic. Thus, I am of course interested in work into such areas, such as the hypo-prior stuff. I personally find monotropism a useful model. It is a model of human attention, perception and diversity though and applicable to anyone. The double empathy problem is applicable to any interaction too. I heard a conceptual term earlier which I thought was very similar called 'symmetrical reciprocity', I find this a much better explanation of social interaction breakdowns than saying autistic people lack a theory of mind.

I am not denying other forms of expertise in what we call autism, just putting forward lived experience as important, as I would in regard to Mad studies. We certainly seem to disagree about how we see this issue, but perhaps have not fully unpacked those differences.

I don't particularly want to split critical autism studies into sub-groupings, but would like to see 'it' embrace a number of different views and perspectives regarding the use of critical theory as applied to autism. I also critique the characterisation of the neurodiversity movement being embedded in what you define as a 'difference model'.

Thanks for saying something about your practice. In terms of counselling and mentoring I have a liking for personal construct theory, despite its potential limitations. I'd be interested in your views on this theory and related practice.

I disagree that the critical autism studies that I represent gets wide coverage, especially in academia. US-based activism has had some coverage, as have the odd hand-picked individual by charities etc.

The Larry Arnold essay was first written in 2004. It was published in 2012 for historical reference. Larry's views have developed a great deal since then, but he did recognise back then that autism was not a 'single invariate thing'.

I think some of my views are much closer to yours than you realise. Some not so.

Damian

Sami Timimi:

Thanks Damian

I really appreciate your last email and I think we have had a productive (if at times challenging) exchange. I have learnt a lot from it and agree that there are some differences but also a lot of similarities and overlap and in particular we are all of us seeking the same ends of trying to shed light on something in a way that we hope will help improve something in the lives of people we encounter and move the discussion in clinical and academic arenas on.

Best wishes

Sami