

The experienced clinician discusses writing his recent paper, and its reception in the field.

28 August 2023 | by Brady Huggett

This transcript has been lightly edited for clarity; it may contain errors due to the transcription process.

## **Brady Huggett**

Hi, I am Brady Huggett, the enterprise editor at *Spectrum*. Recently, a paper was published in the journal *Child and Adolescent Mental Health*. The paper was written by Jonathan Green, a researcher and clinician at the University of Manchester at Royal Manchester Children's Hospital, and Manchester Academic Health Science Center, all in Manchester, U.K. The article is titled "Debate: Neurodiversity, autism and healthcare." There have since been a few commentaries in response to Jonathan's article, and it has generated some online chatter, which is not unusual around these topics.

So we wanted to talk with Jonathan about this paper, why he wrote it, what his key themes are, and also discuss the early reaction to it. That's what I've done. That's the focus of this interview. We talked on August 3<sup>rd</sup>, 2023, morning for me and, and mid-afternoon for Jonathan in Manchester. And before we get going, I'll say that if you are listening to this on a podcast app, on spectrumnews.org, the posting for this interview includes links to some of the papers that Jonathan and I discuss. So that's all you need to know. We'll start here, where I'm asking Jonathan how this paper came about.

[transition music]

All right. So, Jonathan, I think the first thing that we should talk about is your impetus for writing this paper. What were you thinking about and how'd you come up with this topic?

#### Jonathan Green

Yeah. Um, thanks, Brady. Um, I think the, uh, the occasion of writing the paper really came from the current, uh, very fluid, contentious, and often really difficult situation for clinicians, uh, with the current status of autism, debates around neurodiversity, etc. I was asked to write the paper, actually, after I delivered a lecture about the history of autism- history of the autism concept, and how I thought it had altered over time, and, uh, what I thought the current- uh, what I called the paradigm shift, uh, real, real turning, pivoting points now were, and-and they asked me to write this, uh, this contribution after that.

I've worked as a clinician in this field for 30 years or so, and as also a clinical scientist. And I just know the complexity for, uh, clinicians in this field at the moment and the pressures they're under. So this is partly to-to help them.

## **Brady Huggett**

Can I ask, you-you said you were asked to write the paper, that's by the journal, the journal asked you to write the paper?

## Jonathan Green

Uh, yeah. That's exactly, yeah.



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## **Brady Huggett**

Yeah. OK. And I was gonna ask too, who-who you thought the audience was, and it's for clinicians. I mean, really you're trying to lay forth some new thoughts for clinicians here.

#### Jonathan Green

Yeah, I've- that-that's-that is the case, uh, Brady. I, um, I have written some other papers on this topic recent- the last couple of years, which have really been addressed as much or more to the, uh, broad scientific, uh, uh, professional audience, um, and also to the neurodiversity community, and of course, in this modern, uh, media age, you know, that I-I'm totally aware that what I wrote in this paper, although I had clinicians in mind, um, of course, other people will read it, and they have, and they've commented. So, uh, you know, that's just normal these days.

## **Brady Huggett**

So you, I think, most recently, you-you wrote on this topic in October of 2022.

#### Jonathan Green

Yeah. I wrote a-a paper called "Autism as, um, Emergent and Transactional," um, which is- was a theory paper that really folds into this. And perhaps it would be useful just to explain the origin of these ideas, um, which really lay-lay behind the-the argument in the paper.

So earlier in my, uh, career, I, uh, my, uh, my first, uh, area of, uh, research, developmental research actually was in individual different psychology, and particularly in temperamental variation in newborns and, uh, early infancy and its consequence. Uh, so I was, um, very much involved in the-the notion of individual difference and its consequences in development.

And within that, the study of temperament historically, uh, I think was a very interesting paradigm where the downstream consequences of early individual difference, which was largely assumed to be genetic in origin, was, uh, plotted in longitudinal studies. And this notion, uh, arose of the so-called transactional relationship between individual difference in development and the world around the individual.

So I was imbued in that and in the sort of intervention research that was done early on, which showed that actually, with the right kind of intervention early on, one could actually mitigate the downstream effects of early difference and improve, uh, downstream outcomes, but within this transactional context. So, long story short, around 2000, uh, the turn of the century, um, I began with colleagues to apply this idea to autism as a developmental difference.

And basically, we showed in these programs really quite strikingly that actually, you could alter the transactional dynamics early on with autistic difference. And actually, uh, more strikingly than that because that had- that's pretty common knowledge in a lot of intervention procedures, but then actually this-this altered and improved downstream autism, uh, phenotype.



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So this was not done with high-functioning autism. This was done with kids who are largely, uh, minimally-- well, uh, or, uh, didn't have free speech and had reduced IQ. This underlay the paper I-I wrote in last year on, uh, "Autism as Emergent and Transactional." And you can see how the logic came from that. That's-that's the second bit.

And the third bit that underlays this paper is my engagement with the neurodiversity community and autism advocates over the last five, six, seven years, which has been quite intensive. And I've really engaged them, uh, quite deeply in phenomenological work. And, uh, thinking about their own experience and understanding the-the neurodiversity community and advocacy movements and all of those three things together then led me to the kind of position that, um, I'm talking about in the-in the paper here.

## **Brady Huggett**

And so it's- OK, those are the roots. And you've sort of applied this to our current moment, if you will. And I think early in the paper, you said that there is a receding horizon for the scientific goals around autism, which I thought was a really interesting way to say it. Can you sort of expand on what you mean by that idea, that this is a receding horizon?

#### Jonathan Green

That was-that was put sort of purposefully like that to just- I-I think, um- I mean one anecdote to-to exemplify it, when I first worked in autism seriously in the '90s, uh, I was part of the first large, uh, international autism genetics consortium, which was looking at molecular genetics and-and at a big population level and big data. And we started out, I mean, I was junior in the-in the consortium, but, uh, which was led by Michael Rutter at that time.

But, you know, I realized that it started out with basically a modeling that there would be probably six genes of main effect that would actually determine autism. That's where it was at the time, around 1995, right? And what I've seen in that consortium, and we've seen over the- over the time, of course, is that-that wasn't the case, that we've now got maybe 1,000 genes of sm- uh, of small effects, CNVs, plus of course, uh, uh, proportion like 14 percent or so of-of single-gene disorders of main effect that are associated with autism.

So- but if you look at common familial autism, this is a polygenic condition. And, um, so there's a-a receding horizon on the genetic silver bullet, right? Which is what we started with. There's also a receding horizon on, um, biomarker identification, not only a genetic, but at a neuroscience level. So I've been involved in a lot of the early babysibs projects in terms of early neurodevelopmental studies.

Bottom line, we haven't got a-a simple, um, uh, early marker, predictive marker for-for autism in that sense. I- so that's what I mean by a receding horizon, Brady, um, and the idea that, you know, which some, uh, people misunderstand, that a lot of genetic research basically implies eugenics i-is-is kind of



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scientifically nonsensical. We'll never find a-a gene, um, marker, a prenatal gene marker that would enable that.

### **Brady Huggett**

Yeah. So that led you to write, I think that you called it an- right now we are- there's an unparalleled flux in our understanding of autism, right?

#### Jonathan Green

Yeah.

#### **Brady Huggett**

And-and as you said, 1994, everyone sort of thought they-they- we would figure it out, it'd be very simple. That's been not the case at all. And now we're sort of in this area where, um, it's not clear what might be known or what even isn't known yet. And that, I think is what led you to sort of say, "Now we need to think about treatment differently."

#### Jonathan Green

That's true. I mean, I don't wanna under-underestimate, uh, and under-respect the huge science work that's gone on and the amount we've learned from it, but I think what we've learned-

## **Brady Huggett**

Oh, sure.

### Jonathan Green

What we've learned is complexity and-

## **Brady Huggett**

Yes. Yeah.

## Jonathan Green

-uh, you know, we need to take a different paradigm view. And, uh, the other aspect of the paradigm shift is-is like what we-what we mean by autism. I mean, one of the sections in my paper was, "What is 'autism' anyway?" And, you know, and that's come under a lot of debate. And I do think that the advocacy movement has brought into play for us in the clinical science community vividly the lived experience of autism, and that- and the importance of that in our consideration.

#### **Brady Huggett**

OK. So, if we have this idea that autism now is, uh, emergent and transactional, and that's gonna lead hopefully to a new way to treat aspects of autism, I suppose. Take me through how that works and sort of what's needed to be uniformly believed, or not maybe not uniformly, collectively believed in order for that to work. And you-you've laid out three or four things that need to happen.



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#### Jonathan Green

Yeah. I mean, what I suggest is-is that we need to have a more of a shared understanding that what we call autism is rather a dynamic entity. You know, when I first started in the field, there was this, like, quite preformist idea, really, that autism was a neurological, uh, disorder, uh, that emerged over time as sort of biological emergence. Um, and, uh, it was nothing you could do about it. Certainly, in the U.K., it was total therapeutic nihilism that you could do anything about this unfolding, right?

Um, and I think we-we do need to change that. I think the work I've done in-in our therapy program and other people too have shown that no, this- there is, you know, within limits, there is, uh, work that one can do on the environmental aspects around autism that can really cha- substantially change things. So I think we need to do that. And, um, you know, I think we need to seriously realize that we can actually invest in really good early environmental adaptations right from the get-go that could make at least some difference to the evolution of the phenotype.

And I've-I've suggested in the paper that, um, we really need to recast our intervention model to be much more proactive, more, um, preventative in orientation, uh, rather than reactive and firefighting, uh, which is so much of what goes on at the moment. Uh, but there's also the need, and this is another aspect of the paper, uh, we need to, uh, avoid culture wars around, um, you know, uh, fighting about what autism is and, um, which is a really unfortunate aspect at the moment.

And-and so I wanted to try and create a kind of shared language, um, model that-that would be at least reasonably acceptable to, um, both the, um, the neurodiversity community and also to the, uh, community of, um, adults and parents whose, uh, whose children and adults who have major disability, you know, and no one is underestimate- certainly not me, since I've worked with them for 30 years, underestimating, uh, the-the importance of that and the need. So, uh, this, the idea that, you know, that intervention is-is-is inappropriate is-is not compatible with clinical experience. And there's- so there are real dilemmas here that we have to really, uh, talk about together.

## **Brady Huggett**

Yeah. So the-the idea basically in this, you know, as you said, we're in this unparalleled flux of our understanding, is to maybe make a shift from, "Hey, we're looking for these genes so that we can affect these genes," to autism is emergent. How do we change the environment so that this autistic person, this autistic young child, flourishes so that their outcome is improved?

## Jonathan Green

Yeah. That- in a- in a nutshell, that is exactly the paradigm, and it-it-it-it-its orientation is-is to, um, accept and value the difference, but to try and optimize the outcomes as much as one possibly can. And what we can do in health care, I think, is this early intervention piece, but of course, it links with societal change, uh, with change in the workplace and all sorts of other things that are beyond earlier education,



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that are beyond health care to actually within the same model of accommodation to improve flourishing and outcomes.

### **Brady Huggett**

You just-you-you just mentioned, and you mentioned this in the paper, that there's been this sort of fracturing of the landscape. The neurodiversity movement has brought like, uh, just a ton of attention to things that were not being looked at before, honestly, and that- and that has bumped up against the medical community, which is sort of looking at autism as this medical condition, right?

This is the social model versus the medical model that you-you alluded to before, and you're hoping the paper might sort of help stop the fracturing. Do you think it's been able to do that? I know it's early days, of course, the paper's not even out in print yet, but what is your thoughts about this after having been out for a while?

#### Jonathan Green

Uh, well, obviously, the paper in itself won't do it, but, um, I think that I am committed to a-a-a common language. I think, uh, as I- and I wrote about this a bit more extensively in the-the 2000-the 2022 paper on, uh, emergence and transaction that, you know, we have-- part of the whole remit of clinical science has been to integrate the basic biology, basic science, clinical practice, and-and social understanding, you-you know, to have a unified view is-is so powerful. And, um, so how are we gonna do that?

Well, we do need a model, and that's what I'm trying to present here. We do need a model of thinking, but then of course, we need, um, dialogue, and we need engagement with each other. And, uh, I try and do as much of that as I can myself and others that are also doing it. And they'll need to be given on both sides. That's obvious, uh, because there is a, uh, a lot of incompatibility.

You know, one thing I-I don't want my model to-to underplay is the, um, the disability aspects of a lot of autism and/or to overplay how much treatment can do. I think it can do a lot, and we've shown this empirically what it can do, but it-it's not a magic cure. And I think from the other side, there's-there's too much defensiveness about the-the felt threat from neurodiversity language, um, the social model and, uh, advocacy community. And, uh, and it-it sort of, uh, I mean there are de-there-there are trigger areas around which this revolves, of course.

I mean, one is the notion that, um, any intervention or treatment is, uh, is basically destroying autism or under- or-or trying to wipe it out, uh, that sort of eugenics narrative, which is, you know, a-a tough one. And, um, when I'm in the room with autistic advocates and, uh, we can really talk this through, I-I think and hope that there's a- there can be a bit of mutual understanding here. And I hope that the kind of treatment model I'm proposing is more acceptable because this is not about changing or wiping out autism, it is about, uh, supporting it. You know, that's the argument we've made, and I think generally that's been understood and supported by-



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## **Brady Huggett**

Yeah.

#### Jonathan Green

-many.

## **Brady Huggett**

Yeah. So, let-let me-let me ask about that 'cause I think-I think when- you tell me what-what feedback you've gotten on this paper already, but I think the idea would be for a neurodiverse advocate, if they-if they read this paper, they would say what they're doing is trying to lessen autistic traits and therefore make me less autistic, and that is what they're fighting against.

#### Jonathan Green

Well, yeah. This is-this is, uh, a complex, very nuanced, um, uh, argument here. I mean, it's-it's so interesting because it comes up against autism identity. So, there's a social identity model and argument, but a lot of it gets tied to this behavioral phenotype definition diagnosis. Now, this is a complex argument because if people then say, "Well, no, you're- then you are taking away my autism identity," what I say is, no, I'm not, I'm-I'm really not doing that.

But the-the nature of autism development is like all our developments, all our identity develops in over time. You know, none of it's pre-formed. None of us have a preformed identity, and I don't believe autism identity is preformed either. Um, you know, and so one has to-to take this developmental argument, but of course, in the social space, autism identity is a binary, and it's a valued identity. And so that is a very real-a very real dialogue and challenge, a mutual challenge I-I'd say.

But from a- I think what I'd be saying, and the- and this is where I think the phenomenology is important, is that we actually think from the phenomenology work that we've done that the-the core neurodivergent phenotype may lie slightly be-behind what the behavioral phenotype currently tells us, so that if you listen to autistic people and their experience, actually, their experience doesn't really map onto the DSM category.

You know, their-their experience is of an overwhelming world, a huge sensitivity, which often has great benefits as well as difficulties associated with it, an attentional style, which is highly focused at times, and then, uh, feels pretty, uh, chaotic at other times, but again, has some very, uh, powerful strengths to it. And all of this, of course, is from the, um, verbal advocacy and this is often what's criticized about. It's not representative, but it-it's a very important group, and these people can tell us what it feels like to be autistic. And what they tell us doesn't map onto DSM very well.

We may want to alter the phenotype a bit, which may in turn alter what people think of as the autistic identity. And it's not the same as the ADOS thing that we measure and that we change because what I'm



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a-arguing is that what we are changing is downstream effects, which is not quite- which is slightly different. So it's a-it's a subtle argument, but I hope that's clear.

And one other thing I wanna say is that intellectual disability associated with autism is another big issue here. So that for children who are non- and-and adults who are non-communicative, who have- or non-speaking, um, who-who are really cognitively, uh, delayed and autistic, what's their lived experience? Is that a very different kind of thing? And a lot of the time, we just don't know that because we haven't been creative enough in being able to access their experience. And I think that is a-an area that we're gonna need to really look at.

## **Brady Huggett**

I-I wanted to ask a thing too because you-you mentioned- in the paper, you actually mentioned that you'd worked on another paper with three autistic colleagues of yours, and you sort of went back over your earlier lives and you realized there were some similarities in the way that, um, you developed versus the way they developed, and also some differences. But on this-on this paper, you're the only author, but did you run this past some of those same colleagues?

#### Jonathan Green

Uh, yes. Yes. The, um, uh-uh, these ideas have been, uh, talked about with them. I mean, I'm not saying that they would agree with everything I've written here, but they're familiar with these, uh, with the model that I've put forward. And, um, I think I've learned a lot from them, which has also illuminated thethe model. So, uh, Jo Bervoets, who I, uh, reference in the article is one of those colleagues that I wrote that paper with.

So, uh, I'm not-I'm not claiming they'd sign up to this, [chuckles] but, um, you know, that-I-I hope that this is something- my informal feedback is that this is, uh, something that's at least to-to some of those colleagues is-is an acceptable kind of way of framing the thing. Yeah.

#### **Brady Huggett**

Yeah. A couple of things I wanna ask you and then we're done, but one is, what feedback have you seen? Again, it's not out in print, but it is online, and as you said, it has been disseminated widely. What feedback have you seen? I mean, I have some- I have seen people online saying things like, "This is eugenics," as you mentioned, right? Um, what-what feedback have you gotten?

## Jonathan Green

Uh, well, there are- there are a couple of, um, published commentaries on the paper. So the-the journal, uh, commissioned, uh, actually three commentaries, uh, but two are- two are in at the moment. Um, and so they're available, so you can see those. One is from a-an autistic, uh, advocate, uh, academic, and the other from a clinical science, uh, colleague. Um, so there, you'll see there- I mean the-the, um, if I



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distilled it down, the-the-the feedback from the clinical science colleague is largely, um, I-I would say supportive of the model.

Uh, the-the autistic, uh, advocate, uh, colleague, particularly focused on a-a lack of, um, in this, what-in my paper, on a lack of attention to autistic identity. And I think she's right to do that. I don't think I have talked about that, uh-uh, very much. Uh, partly it's because I don't feel really qualified to do so. She makes some points that, you know, that-that there's not enough attention to that. And I, you know, I do accept that that is a-a legitimate area where we have to really wrestle and discuss together about those things 'cause there are some paradoxes in there.

Otherwise, um, online, yeah, there's been, uh, some of the sort of Twitter commentary around eugenics, which is, you know, I think is a bit, um, it's like any-anything that in- that-that suggests intervention at this current time can provoke that, uh, kind of feedback. And I hope I've tried, really tried hard to, um, to explain why I think that this, the kind of intervention certainly, that we are talking about here, um, its-its aim is to- is to validate and to support, uh, neurodiversity rather than, uh, get rid of it. Um-

## **Brady Huggett**

Yeah.

### Jonathan Green

-so-

## **Brady Huggett**

Yeah.

### Jonathan Green

-uh, you know, you do what- one does one's best with that.

## **Brady Huggett**

Yeah. So just the final question. You know, this-this paper mentions neurodiversity throughout, and the word has, I mean, grown exponentially since it was first coined. And I think, almost that everybody has their own definition of what that word means, and I'm wondering how you would define neurodiversity.

#### Jonathan Green

Um, yeah. So I-I don't think I would want to, um, hazard an overall definition because, as you say, this is a term that has been used so differently by different people. I mean, of course, it-it began as a-a-a term of, uh, assertion really, of the importance of um, you know, neurological differences. Um, and it-it-it came from the, you know, neurodiversity community, um, uh, as a-as a- an idea.

And I think it really applies to the idea that there is a range of brain difference. Uh, and I suppose whatwhat is, um, controversial about it or-or radical about it, is how wide you take that net. You know, we-we



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could, you know, think about, um, dyslexia, dyspraxia, dyscalculia, you know, these things are all very, uh, you know, and they're not really pathologized as it were really within the developmental science. And then you- then you can think about ADHD, uh, another neurodevelopmental condition that is, as it were, "pathologized", intellectual disability, Tourette syndrome, anorexia, schizotypy.

Uh, so it's, uh, how broad you-you embrace the differences here. So that's an important thing, is like there's a range of, as it were, normative variation. And it's how broad, and I think the neurodiversity community would often wanna argue for a very broad definition of-of-of this. So, uh, and then, of course, there's the idea that-that the concurrent with that is the-the fact that the people should have equal social rights, um, and, uh-uh, so as a sort of social activism.

Um, you know, I think that then if you are- OK, so how do I respond? Well, basically the idea is in essence intuitive to me from, as I said, I started off with the idea of individual difference, um, uh, research. And a lot of this is just a reframing of that. Uh, you know, we know a lot of the genetics research has suggested there are a lot of common genetics, uh, between these different conditions. I'm personally more of a splitter than a lumper. So I like to keep, uh, these-these individual conditions, I think have very particular characteristics. And I don't wanna lump them all together into one thing, but there's-there's is clearly a family of neuro-neuro difference. [chuckles]

So, yeah, I think, um, neurodiversity is quite an interesting concept, both scientifically in terms of shared genetics. Um, you know, and you maybe were, uh, familiar with the essence, uh, model of, uh, Chris Gillberg, which he's talked for many years about how all these conditions are all somewhat part of a one group. Um, and I've personally not really agreed with him, but, you know, it's there, that he's argued that for many years. And I don't think there's a big difference between that and a lot of what the advocacy community say from their own lived experience perspective, to be honest. And I think we can learn a lot from each other about that.

#### **Brady Huggett**

Uh, that was a- one of the longest definitions of neurodiversity I've ever heard, but-but a complex one. I like it, thank you. Thank you. Um, that's-that's all I had, Jonathan. Uh, thanks for taking the time to talk about your paper and-

## Jonathan Green

OK.

## **Brady Huggett**

-uh, good luck with it.

### Jonathan Green

Thank you.



**TRANSCRIPT** 

# 'Emergent and transactional': How Jonathan Green is rethinking autism and interventions

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