

Transcript, Noncompliant: A Neurodiversity Podcast

“What outcomes are we looking at?” Talking with Dr. Andrew Whitehouse about the shifting course of autism research & services

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Transcribed by Julie-Ann Lee

[Intro music: Jazzy synth pop music]

Anne: Welcome to Noncompliant, A Neurodiversity Podcast. I’m your host, **Anne Borden King**. My guest today is **Dr. Andrew Whitehouse**. We’ll be talking about autistic life, gut hype, same-foods, the problem of pseudoscience and the shifting nature of autism research.

Dr. Whitehouse is an Angela Wright Bennett Professor of Autism Research and the Director of CliniKids at the Telethon Kids Institute. He is also a Professor of Autism Research at the University of Western Australia and Research Strategy Director of the Cooperative Research Centre for Living with Autism (Autism CRC). He has published over 300 peer-reviewed journal articles and is an advisor to Australian State and Commonwealth Governments, various state and Commonwealth Governments I should say, on policies relating to autistic children. He was awarded a Eureka Prize for his research and in 2023, he was a Western Australian of the Year award winner.

I’m so honoured to have Dr. Whitehouse on the show today. Andrew, welcome.

Andrew: G’day Anne. Gosh, that was boring. I need to get a bit of a life, don’t I?

Anne: (laughs) We’re going to talk about your work in autism research and about autism research in general. But, I want to kick things off by discussing your work in science literacy for the general public because you wrote a very interesting book called [Will Mozart Make my Baby Smart?](#) It looks at some of the myths of pregnancy and early childhood development and it really relates to the discussion in our previous podcast with [Dr. Paul Offit](#) about how we conceive of parenting in this moment and how marketers latch on to parents’ anxieties about raising children today.

Could you tell us about how you came up with the idea for your book?

Andrew: Aww, thanks Anne. Yeah that was great, great fun writing that book. It really came around the time that I was having my own children, and I was perhaps not surprised but still shocked by the industry that surrounded children and parenting. There are not many more

vulnerable times than when you're starting to have children because your life changes dramatically and forever. And you will do anything to support that child to be whoever they want to be. And what I was constantly shocked about was just how much information parents were bombarded with, much of which seemed to be related to science but actually, you scratch beneath the surface and it wasn't there at all. And I've always loved writing. It's great fun to dig deep into something, and try to communicate something that people think is really complex but at its core, it really isn't complex.

I just sought to use a bit of time that I had to write, find myths or at least sort of "old wives tales" about childhood and pregnancy and to actually dig into the science to understand if there is any validity there. In some there is, but most there isn't, and it was really great fun, and more fun that it was optioned off into a TV series which was also great fun as well.

Anne: That's amazing, and we'll put a link to the book in the podcast on the podcast blog. It's interesting that you're talking about these industries that rise up based around anxieties that parents have... because of course, there are a lot of industries and little cottage industries and big industries around *autism* as well.

You told *Spectrum Magazine* in 2021 that, "my overwhelming feeling is that we accept and perhaps even expect lower standards of clinical evidence in the autism field, than in almost any other. The dangers to families are so obvious, not just in terms of safety but also in the emotional, financial and opportunity costs." We can see how research sometimes does end up being monetized to sell things that don't really work, much like we were just speaking about, and when it's autism families, they're particularly vulnerable.

Let's talk about that issue of clinical evidence, though. What is the kind of historical background for this evidence problem that we have in autism research.

Andrew: Oh, it's a great question. Look, I'm so lucky that my professional life has really spanned most of the modern history of autism. When the fourth edition of the [Diagnostic Manual](#) came out in 1994, that was sort of a large expansion of the diagnostic boundaries where it used to be kids were diagnosed with what was called childhood autism only if [they] were showing really quite significant disability. What the fourth edition of the Manual did is it expanded the diagnostic boundaries so that we started diagnosing kids and adults who may be showing those core behaviours of autism but may have no intellectual disability or language disability as well.

And so that was really the first boom of the large numbers of people being diagnosed with autism. Prior to that, autism was quite a rarely diagnosed condition. The prevalence went up, and up, and up, and for so long we were chasing our tail and trying to provide services to these really large numbers of kids being diagnosed. And we really never stopped to take our breath and to look at what the evidence is in what we're providing. Part of my work in Australia is to

developing Australian guidelines, national clinical guidelines, that essentially guide how we do clinical practice.

And through that work, what we've been able to do is understand some of what we as "truisms" in the field, and then trace it back and back and back, right to its original evidence source and you look at it, and there was actually very little evidence there in the first place. Where we're at in the moment is we had large numbers of kids being diagnosed but we never stopped to recalibrate as to where our evidence is and actually what are is what we're doing right now aligned with that evidence.

I mean, I'm lucky enough to work in a medical research institute of many different health and medical conditions for children. There are zero other, *no* other areas of health and medicine that would accept the low standards that we accept in the area of autism. And I see that as a complete failure of our ethical obligations to kids and families. They've got one shot at their lives, and we need to give them our best evidence so we can ensure that they live the lives that they want to live.

Anne: We touched on this in an episode that I did with [Micheal Sandbank and Kristen Bottema Beutel](#) too... why do you suppose it took so long for autism research to begin to really develop standards for the research, and why, for so long, was this really problematic research allowed to build these "truisms" that have not been true? Why do you suppose that is?

Andrew: I think there's a large element of mystery that comes along with autism. We have this absolutely beautiful and gorgeous child in front of us, who's developing differently for reasons that we can't necessarily provide an easy answer to. That's not to say that we don't understand the reasons, but that's to say there is no easy answer in that, and that is very, very challenging to understand and there's no simple answer as to how we can support that child to be whoever they want to be.

And so into that void come a large number of different "options" that families are offered. And we haven't had the regulatory frameworks in place to enable us to actually say that compassion is something, but actually evidence is everything. And so I take the view that the large majority of people who may be offering non-evidence based therapies, they're very well meaning and they have great empathy for the kids and families, and of course there is a small proportion who are straight out charlatans. But my feeling is that if you have overwhelming compassion, you've got to have great aim. You have to have very precise aim, and the way that we do that is thorough evidence.

I think there's a couple of things. Number 1 is that there's the mystery, which enabled a void which enabled people to flood that void. And then we had weak regulatory frameworks, or non-existent regulatory frameworks that were able to be exacerbated by, in some cases by very well-

meaning people, but other people who are straight-out charlatans, and of course then the financial implications take a hold upon that and we get into this horrifying cycle where it's very difficult to call back.

Anne: Right, because it's very normalized also in policy, right? A lot of this very flawed research is a backbone for how programs have been funded over the years.

[09:56]

Andrew: Well, that is correct, and I'm very lucky to be asked to review health and disability systems around the world, and I can tell you that this is something that is universally a challenge all around the world, certainly in Australia where we have a pretty good system.

The challenge of providing families who have a child with disability the necessary choice and control over their own life to use public or private insurance funding, to choose how they can support their own lives – that's a human right. But we also need to have those regulatory frameworks to narrow down those options so that that money's only being spent in ways that we know has the possibility to help them. That's a huge challenge within Australia.

Then of course you have more universally public systems like Canada and the U.K. where there is just simply a dearth of money in the system. And then there's the U.S. system where people do look at the U.S. system with slight horror at the challenges that families may encounter when they may not have private health insurance, but even when they do have private health insurance and there are certain therapies that are mandated that may not be necessarily aligned with best evidence. That's a really wicked problem to have, and that's a very challenging system to understand how you can navigate out of that.

Anne: It is, especially if you look at insurance mandates, or public insurance mandates in Canada, where certain methods are just accepted as evidence-based, even ones that have *weak* evidence [like ABA] and they're really built into the systems. I imagine part of the job of doing this critical analysis and this synthesis of research evidence which is something that you've been working on, is showing what's evidence based and what isn't. Then you have to translate that for regulators and policymakers so that they can understand how they need to shift, is that right?

Andrew: That's exactly right. This is not work that's for the fainthearted (laughs)

Anne: (laughs)

Andrew: Having trained clinically and now working in science, I've been so privileged to be able to interact with thousands of families and have understood, I mean genuinely, the deep trauma

that comes from not having a pathway... for not having a roadmap from that point of diagnosis, or even the point of identification of developmental difference and the challenges that our systems provide on families above and beyond.

So, what can we do as systems to actually smooth that path – not be less than the sum of its parts, but more than. That was part of the challenge that I took up in my own home country of Australia: how can we actually develop evidence-based guidelines that guide families within our own peculiar system? And these need to be system-specific, because of course we're all different, we all have different cultures and we all have different systems.

But to provide that evidence-based guidance is to also put yourself in the firing line of interests... Interests that are out there that are often well-meaning, that have their own beliefs about how we best support kids, but also interests that perhaps may be less than well-meaning, that simply just have financial incentives. That's what I sought to do within the Australian context: how can we actually develop that guidance, and frankly in doing this to have a complete tunnel vision focus that at the end of the day this is *about giving kids and families the best shot at their one life, to be whoever they want to be and be unapologetic about that.*

Anne: I suppose it's kind of difficult to untangle the intentions from the vested interests, and I know that if someone's been making a lot of money selling a therapy that they really believe in, that is quite profitable for them, where they may even be involved in a larger structure that's offering this therapy.... It may be the only kind of therapy that they are educated to even teach, and so it can be even quite threatening to someone who's doing a form of therapy where its validity is being questioned.

And I know you've encountered some resistance, as you mentioned, from some practitioners for the work that you've done, including being threatened with lawsuits. I'm wondering: how do we get past that? How are we able to make that kind of shift without all of this tension, or is the tension between older methods that may not be as evidence-based or even new methods that aren't as evidence based, where people that practice those methods that feel threatened...

Andrew: Yeah.

Anne: How do you manage that kind of tension?

Andrew: It's a really tough balance, but I guess this is my message to the field. I think it's twofold. Number 1 is that we need to approach every conversation with the courage to go outside our comfort zone. That's absolutely critical if we're going to engage in tough conversations.

But, simply the second one is humility. What I've been genuinely surprised at within the field is the lack of humility that I have seen amongst all quarters. We're all guilty of this. And that's approaching conversations to say that "I don't have all the right answers. And in fact, some of my deeply held beliefs may be wrong." I think we have a chronic humility gap (laughs) in the field.

Anne: (laughs) Yeah.

Andrew: Can we start approaching conversations with that that mindset, that actually "I have been working in this way but I simply don't have all the answers and I am open to understanding."

Now, the second kind of add on to that is that we need to come up with a common truth. And a common truth is what we're seeking to do. We need almost a shared narrative around what we are seeking to do and our mission here, and I do think that it's uncontroversial to say that we have a shared mission that when we're talking about pediatrics, we have children and families who have this enormous well of love for each other. Just the greatest asset that we have as clinicians is that well of love between kids and families. What we need to do is to ensure that we provide the families the tools, genuinely the objective best tools, so that they can meet whatever they want to be in their whole lives. For that we need to lean back on true and solid evidence. And that to me is a completely uncontroversial narrative, but we need to believe it and we need to have that common understanding of it.

Anne: I agree, and I have a question about the gathering of the evidence because something can be evidence-based, for example, but there really hasn't been a lot of resource directed toward that evidence base...towards doing the clinical work to study it. Whereas older methods tend to have had *a lot* of research done on them because they had a lot more time to do the research. So for new and emerging approaches, how do you deal with that kind of difference where there really might not be as much study for something even if the [smaller] study is robust and really seems to show evidence? How do you how do you work with that?

Andrew: well, I think we need to be entirely intellectually faithful here, and that is that there's new and emerging evidence in every field of health and medicine and they simply don't get into clinical practice until they have done the work to ensure that they are, number 1, safe. That's our first thing, safety.

And secondly, that they have evidence for efficacy, so that they are promoting whatever outcome we're seeking to promote. So it's a really hard answer to convey, but I try to be intellectually faithful about that. I have new and exciting things that I think are really exciting all

the time, but we must go through all of those processes, and that's there's no shortcut around [the fact] that we must go through those processes before they reach the clinic.

I think, also in the area of autism, I would add the caveat that things that might have had considerable research done on them previously, may not have still gone through that process! Not, all evidence is created equal. That's a really hard message to also convey, but we also have to be intellectually faithful here that not all evidence is created equal is simply true. Certain study designs do not carry the same amount of evidentiary weight that, for example, Randomized Control Trials do.

Anne: Mm-hmm.

Andrew: It's not necessarily about the length of time that these events are studied but the process and the rigour of the study that they've gone through. And I am a strong advocate that there is no shortcut around that, no matter how exciting things are, and that's because of our ethical obligation around safety and efficacy, and that's the same that we would expect and only accept in every area of health and medicine.

[19:51]

Anne: That's so important, and the point that you raise about RCTs is so important because much of the older research ...and even current... isn't often based on RCTs and there's a lot of issues with bias.

The other part of it is that the goal has changed, because of the Neurodiversity movement, because of parents and autistic people saying that really the goal of autism therapy is much bigger than the older goal... which was compliance, right?

Now the goal is more focussed on inclusion and equality, more based around a social model of disability, and really different than some of the older goals, so even when you look at older research--and most of that is flawed, but despite all those flaws even--one of bigger flaws of the older research is that really it's trying to prove that it can create compliant children. Whereas the goal is a little bit different now. The goal is really for people to have a good quality of life and to be happy and feel fulfilled. These are kind of newer goals, so the thing that we need to figure out is: what should the goal of an autism service be? What should we be trying to prove that it achieves?

Andrew: Completely, and there is a huge amount of research around this as well. What outcomes are actually we looking at now? And again, that requires a huge amount of humility because what I have observed in this discussion is that the Neurodiversity movement has

shifted the narrative around ahm what is a good outcome. ...And there's definitely a view that we need to evolve beyond the [old outcomes], and so what is a good outcome now?

What I've observed, is that there has been at the fringes of the debate, on all sides, is that there has been a discussion about how "only certain voices matter" in this discussion. And I've seen parents cut out of it; I've seen neurodivergent adults who may be highly verbal cut out of it, because they are not necessarily representative of everyone; I've seen clinicians and researchers cut out of it; but the point of it is that everybody here has a really important perspective to offer, and that and that humility is so important in this area to actually truly start to come to that common understanding.

And then when we get to the evidence that supports that, well we do need to go through that process and there's no easy analogy here... I'll say an analogy that I'm sort of thinking about right now but of course, please, it's very clunky as an analogy in the context we're talking about... but there was a time in the area of talking about homosexuality, that the goal was to try and turn gay people into straight people...

Anne: Yeah.

Andrew: ...that was the focus of mental health services and I'm talking decades ago. Of course, we've come to our modern understanding about human diversity and that outcome is no longer something that we're seeking to pursue, fantastically. So what we had to do is go through a whole new scientific process to look at the new outcomes around self understanding, around self acceptance, and then around self expression. And that was a whole new scientific process as well. So while that's a really clunky analogy in what we're talking about, the main points still hold true in that if we are seeking to create different outcomes, we have to get evidence as to what processes are actually truly going to get us toward those outcomes, so we can give families and kids the very best shot that they have.

Anne: That's great and it's amazing the work that you're doing. We're going to talk in a moment about some of the work in your clinic, but I want to talk about your paper about the gut microbiome for a minute, because you and your team explored this hypothesis that the microbiome is causally related to autism... that's the theory that autistic people have a different gut microbiome that drives their brains to be different, and some people seem to be asserting that it's inborn. As you put it, though, when you're describing this hype around autism and the gut microbiome, in your words "the excitement was misguided".

What were your findings with that study?

Andrew: Yeah it's a really interesting one. Thank you so much for bringing this up. This is actually the work led by **Jack Gratton**, and **Chloe Yap**, fantastic researchers and I was really lucky enough to be along for the ride. There's been a huge amount of interest in gut microbiota-- that's the little bacteria in your gut--and how it relates to brain development. And certainly in the area of psychiatry, it's been a huge area of interest.

Look, it's uncontroversial to say that gut microbiota does influence neurodevelopment...our brain and our gut develop from similar structures within the womb, and the gut has its own nervous system – the enteric nervous system... it's how we know when to go to the bathroom, it's how we know when we're hungry. So you know there's all sorts of links here. The last ten years there's been a huge amount of interest that all of a sudden “we are going to identify new causes why brains might develop differently to what we typically expect, and it's going to be related to gut microbiota.” We embarked on this study, really, with that kind of understanding that actually we may be able to identify new biological pathways to autism.

What we actually found was something quite different. And so we pursued the data wherever it took us, and what we anticipated that we would find was that actually children with a diagnosis of autism would have different gut microbiota compared to typically developing kids or neurotypical kids. We found something along those lines, but something a little bit different. Yes, we did find some differences in the gut microbiota in the autistic kids. But actually what we found was the gut microbiota was really only majorly different in those kids with selective diets. What we found was that rather than the gut microbiota being associated with autism in and of itself, it's actually the selective diets of those children associated with sensory sensitivities and all the things we know can be associated with autism that is driving differences in gut microbiota.

And so rather than a causal pathway one way, it's actually a causal pathway another way. It's that an autistic characteristics and behaviours which can drive food selectivities, driving differences in gut microbiota...a really startling finding but pretty simple when you think about it.

Anne: It is, especially if you understand the concept of “same-foods”, and the fact that many autistic people like to eat the same things, a lot. So eating these same-foods isn't something that you found, that doesn't impact behaviour either? It's neither nature or nurture... is that correct?

Andrew: Yeah. You're exactly right on that front. I mean, this is not to say that diet is not important. It certainly is and that's what our study found, that we need to find ways to help kids receive balanced diets, because those balanced diets are certainly important for their mood, and ultimately for their brain development. But the idea that gut microbiota differences is a *cause* of autism – certainly our study did not find evidence to support that.

Anne: That's so interesting. A lot of the work that you're doing is very interesting in your clinic as well, where you're really targeting what you call "the mismatch in communication styles" between parents and autistic children. Could you describe a little bit about that work?

Andrew: Oh, absolutely. Look, we're heavily influenced by families... parents of very young children, and trying to help parents connect with their neurodivergent children. Not necessarily in the way that we would typically connect with kids but in the way that neurodivergent kids may want to connect with us. Of course this goes back to the Double Empathy problem, that actually [is] part of the issue, in fact a large part of the issue is us trying to understand how we can best match what we do to the worlds of our neurodivergent kids. And so what we're seeking to do is to actually, we understand that kids develop differently quite early in life and while we might diagnose autism at age 2, 3, 4, 5, 6... actually we understand that kids develop differently early on, often in the first year of life.

So, what can we do to help parents at that very early age [to] adjust the social environment around the child... that means how they interact with the child... to help the child learn in the way that's best for that child. Not necessarily the way that we think is best for that child to learn but how that child can learn the way that's best for them. We've done a number of clinical trials, particularly with this support called iBASIS which is helping parents understand their children, number 1, their neurodivergent baby, understanding how important they are to their babies' development and how they can then modify the way that they interact with their child to learn in the way that's best for them.

And it turns out that through a series of clinical trials, that actually this is really effective in supporting the child's development. That's really a large part of what we do. How can we help parents of babies connect very early on in life, so that they that child is getting the optimum social environment for their neurotype. It's really the development of a new clinical pathway rather than "wait and see, wait and see, diagnose, then provide intervention". What can we do to actually identify and act to ensure that that baby is getting what they need? And that means that compassion, that understanding and that true connection with the parent from the very earliest moments.

[30:43]

Anne: Wow! I mean that sounds almost like a praxis of the double empathy problem where you're looking at how non-autistic parents and their autistic kids will communicate differently, see the world differently and then building on these differences to find the common ground and the connection to create, like you said, an optimal environment where there can be quality of life for the child, because they are able to connect with the parent--and also quality of life for the parent because they can understand their child because that's really one of the main things

that parents talk about with having an autistic child is trying to find ways to communicate with each other.

So, what are the projects that you're looking forward to working on in 2024?

Andrew: Oh, I mean, we're seeking to do a number of things. My main goal is not necessarily that basic science-level sort of understanding of mechanisms, but it's really about how we can get systems working for families. Having children develop differently can, you know, there are obviously many joys associated with it. There are also many challenges, and what we need to [ask] is how can we get governments to make systems that provide more than the sum of their parts in terms of supporting and nurturing that family, rather than less than... rather than simply a barrier.

I see a lot of my role at the moment is that. How can we get systems to transfer from *wait and see* to *identify and act*? How can we get neurodevelopmental assessments into something that is briefer, less costly and informative towards future clinical management...and then how can we actually get systems to fund and match kids and families with a roadmap that is specific and tailored to them? My research goals are really in the nexus between clinic and policy, and it's a bit of an untraditional research path, but what I certainly find is I get a great deal of joy [from] working with governments to get them to focus all of their efforts in helping... in the same direction to help the kids and families be who they want to be and meet systems that embrace them and give them that real boost to accelerate in their child's development.

Anne: I like that you use the word *joy*. I mean it does really sound like joyful and rewarding work. And I hope it's a model, outside of Australia as well, for Canada and the U.S. and other countries to really be looking at the kind of work that you're doing, and "more of that please!" is what I would say.

It's been just an honour to speak with you and we'll be sharing much of your work on the podcast blog as well, and hope to be speaking with you in 2024 more about the projects you're working on. Thank you so much, Dr. Andrew Whitehouse for being on the show.

Andrew: Amazing Anne. Thanks so much for having me.

Anne: We were speaking to Dr. Andrew Whitehouse. He spoke to us from Perth.

[Outro music: Jazzy synth pop music]

Anne: You're listening to Noncompliant: a Neurodiversity Podcast. I'm your host Anne Borden King. Noncompliant is recorded at MCS Studios and transcribed by Julie-Ann Lee. This episode was engineered by Lucien Lozon. Thanks to our team and thanks for listening.