

Is there an Autism Industrial Complex?

Interview with Professor Alicia Broderick

Noncompliant: A Neurodiversity Podcast

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Transcribed by Julie-Ann Lee

[Intro music: Jazzy synth pop music]

Welcome to the Noncompliant podcast. I'm your host, Anne Borden-King. Today's guest is Alicia Broderick.

Alicia Broderick is a professor of Education at Montclair State University in New Jersey, where she is a Disability Studies scholar and a scholar of Critical Autism Studies. She's worked alongside autistic people for more than 30 years and been an autism scholar for more than 20. Today we'll be discussing her new book The Autism Industrial Complex: How Branding, Marketing and Capital Investments turned Autism into Big Business. This book, which is published by Myers Educational Press, traces the 80-year-long cultural, political and economic history of autism within capitalism--and it's an eye-opening read. We'll talk about how people are making money off autism and off of myths about autism and I'm going to be asking also about how industry greed has gotten in the way of useful approaches that can help families.

Finally, we'll have some words for families of newly diagnosed kids about how to find the best approaches and how to sift through all of the hype.

Alicia, welcome to the show.

Alicia: Thanks for having me!

Anne: We're going to talk about the title of the book first: The Autism Industrial Complex. I want to give listeners some background on the term because it recalls the concept of the **Military Industrial Complex**.

This term was coined by U.S. President Eisenhower in 1961 in his farewell address from office. Eisenhower described the military industrial complex as the economic relationship between the arms industry (that is, the companies making and selling military equipment), and the military itself, and the policymakers involved in military funding decisions. Eisenhower described the

military industrial complex as a threat to democracy, saying: “In the councils of government, we must guard against the acquisition of unwarranted influence by the military industrial complex”. Since Eisenhower’s time, we’ve seen his fears come to fruition, of course, in the nuclear arms race of the cold war years and in subsequent endless wars we’ve all been funding with our tax dollars, in the militarization of schools and many, many more instances.

I’d say the military industrial complex kind of typifies a broader problem within our political system...that interest groups and lobby groups with a lot of money are able to sway politicians through donor dollars, relationships and pork-barrel politics to make political decisions that are not in the public interest, but rather in their own interests.

What I took away from the book really was that there is an Autism Industrial Complex that is doing something quite similar. Alicia, your book makes a compelling argument that there’s also an Autism Industrial Complex that “autism is big business” and [the autism] industry has kind of a parasitic relationship with autistic people.

So, maybe we should start by talking a little bit about what this autism industrial complex is.

Alicia: Thanks, Anne. Yes, I see the autism industrial complex as really being very, very analogous to kind of a logical outgrowth of the military industrial complex. As you pointed out, Eisenhower talked about how important it was to guard against misuse and abuse of power within the military industrial complex, particularly when what you have is what he called *entrenched profiteering* and *ideological monopoly*; and that’s really what we have with the autism industrial complex.

Just as the arms industry became so profitable that it became a thing that people were willing to prop up just because a lot of people were making money off of it, right? Not because we necessarily needed it militarily. The same thing has happened with autism. Because we now have an industrial complex – primarily interventionist, but there are other facets of it that I talk about in the book where autism intervention is now so profitable that it’s no longer being driven by what is best or just or right or let alone desired by autistic people. It is being driven by what is most profitable because it is in fact an industry – a for-profit industry. And as soon as you start making profit off of something, then that becomes the driver for what happens in that industry, rather than the needs of the people you are allegedly supporting or serving or helping, right?

The combination of profiteering and capital in sectors that should be public service [and/or] public health--that’s where it becomes really, really problematic. I argue in the book that the autism industrial complex is essentially 40 years worth of architecture. A lot of people when I say *autism industrial complex*, what they immediately think of are autism businesses, right? They think of the autism industries. They think about all those ABA consultancies out there that are making a lot of money. They think about autism pharmaceuticals, they think about all kinds of diagnostic sorts of infrastructure. And all of those are components of the autism industries,

right? In the same way that Haliburton and Boeing are parts of the arms industries...but they are not the industrial complex.

The industrial complex was built out of *ideas*. The industrial complex involves [public relations] and it involves rhetoric. The industrial complex is what convinces us this industry is necessary, no matter what. And for the first 40 years of the existence of the idea of autism, the industrial complex was being built. By that, I mean ideas about autism were being presented for public consumption that pretty much convinced everyone that “of course, autism requires intervention”.

Once we had accepted that idea then we had this context where when you don't have to justify the existence of your industry, then you have people asking you for it and then the commercial opportunities tend to proliferate after that point.

Anne: Right, and when you say the industrial complex, are you referring to the marketing machine, like generally how people created this idea that they could use to market certain services and to be able to justify really, really high expenditures through the health system, for services that aren't necessarily based in evidence?

Alicia: Yes, that's a big part of it. The marketing is a big part of it. I'll be clear, the autism industries on a small scale have been around almost as long as the idea of autism has been around. If we go by Leo Kanner identifying autism in 1943 in the U.S. – if we use that as a marker, by 1952, in the U.S. autism was a category in the DSM II, the Diagnostic and Statistical Manual of Mental Disorders which is what's used to essentially bill for services if you're in the business of providing psychological or psychiatric services.

From that point on, the earliest intervention industry was psychotherapy for autism. That was the dominant recommended intervention for autism, and it was commercial and it certainly made some money--but it wasn't large scale. It wasn't this big ubiquitous ever-present *thing*, right? And mostly the people who were being treated in psychotherapeutic interventions, mostly they were institutionalized kids. There was not this widespread market.

So, the industrial complex involved a couple of things. One, it involved, as you said, the marketing, where they really scaled up...when the behaviourists came on the scene mid-late 50s and really took over from psychotherapy as the dominant intervention idea.

Anne: Yes.

[09:36]

Alicia: They were marketing their *stuff*. They had lots and lots of stuff they were marketing, right? Little mechanical things, including shock devices and other kinds of things that weren't being marketed for the purposes of autism intervention. But again, their market was pretty small. They were marketing those devices and the services that went with them primarily to institutions. Kids that were already in institutionalized psychiatric care, so a pretty small market.

The idea that we should broaden this autism intervention market really started to percolate, I believe within the behavioral industry, in the early 1970s, between the early 1970s and the late 1980s. Academic behaviourists did a lot of work on trying to figure out: how do we generalize this intervention to a broader context? How do we get it out of the lab and into homes and into schools, because that's going to give us a great, huge broad market. So we had the academic behaviourists that were working on that, sort of methodologically creating the necessary research base to make that argument.

But, then in 1987 as you put it, the marketing push began. When they really, really started a strong marketing and rhetoric campaign that basically started selling autism intervention almost directly to families...When I say marketing push, what I mean by that is this *little treatment effect study* that was done by Ivar Lovaas, published in 1987...not a lot of people read treatment effect studies published in academic journals, [but] this got a lot of public press. It got covered in mainstream media. There were public memoirs written – things that ordinary families consumed...

Anne: Right.

Alicia: ...and so they began consuming these ideas about autism intervention and the key of that pivotal turning point of 1987 was Ivar Lovaas' decision to skilfully deploy rhetoric rather than dry scientific language to sell his ideas...because in 1987 he started selling the idea of 'recovery' from autism.

Anne: Mm-hmm.

Alicia: And that idea is really what drove the beginning of the rapid scaling up of the autism behavioural intervention industries. So, that first sort of 10 to 15 years after that was really just marketing the ideas that were circulating about, you can *recover* this child. It was this strong sense of hope being deployed and also a pretty strong sense of fear being manipulated. "If you don't do this, your child will be institutionalized forever," right? So they were really manipulating families' very understandable but in many ways, very ableist fears about what

might happen to their children. [They did this], I argue, in the interests of effectively selling an intervention industry.

So, that's the first 4 decades of the building of the industrial complex-- the selling of the ideas that "autism is bad, autism is tragic, it's catastrophic, it's not something you can live with. It's something that must be intervened upon, and by the way here we have this intervention that we're happy to sell you, and it might recover your child to presumably to being non-autistic or normal". So, that's like the first half of the ground-work of the intervention complex, that sets of ideas, and the rhetoric, and what I call *branding*- branding and marketing, and the consumption of all these ideas.

The second part of the industrial complex is really the bureaucratic, the legislative, the policy – the technocratic architecture. The stuff that makes commerce work, the stuff that makes money more easily change hands from here to there. We didn't just have suddenly a bunch of random behaviourists go and hang out a shingle in 1987 and then boom we've got the autism industries.

Anne: Right.

Alicia: There was a lot of policy--and legislative and bureaucratic and technocratic labour--that went into making that happen. Now that that's all there, you can make money...very, very easily on autism intervention, specifically because the architecture is there.

But the architecture was built by and large by the behavioural intervention industry and so it should be no surprise to us that the behavioural intervention industry monopolizes the intervention industries, because they're the folks that put the infrastructure in place.

Anne: Right.

Alicia: Right. To me that's the distinction and the industrial complex is the architecture of ideas --the ideational infrastructure or rhetoric, ideas, language, the stuff about you know recovery, the stuff about how bad autism is, the mass marketing for consumption all those sets of ideas-- and built on the heels of that is all of the quietly (but very methodically) built infrastructure.

I'll give you an example of what I mean by that. So, among the major pieces of infrastructure, one of those was the constitution of the BACB – The Behaviour Analysts Certification Board. This was constituted in 1998 in the state of Florida in the U.S. as a non-profit for the purpose of certifying various levels of Behaviour Analysts. This is really, really crucial to having an industry because, if you want to for example create... let's say we're trying to build an industry out of social work, it's kind of helpful if there are such thing as certifications.

Anne: Of course, yeah.

Alicia: You can't go from one state to another state, let alone to go to Canada or a different province, or anywhere else if you're just like "I've decided to call myself a social worker." You have to build a profession, build certifications, build professional recognition and all of that, and that architecture started in 1998. So that was an important piece of it.

Another example, the final one I'll give you is... it's a tiny little thing but it's a very important little thing. A number of different entities spent a number of years lobbying in the U.S. for permanent billing codes for ABA intervention. And what I mean by that is in the U.S. the way medical insurance works we have largely privatized health insurance and in order to bill for a service, there's a byzantine set of codes that go along with any kind of provided service. And for a number of years, ABA or Applied Behaviour Analysis was kind of a temporary billing code.

Folks in the behavioural autism intervention industries did the very boring and very technocratic and bureaucratic labour of ensuring that the American Medical Association created a permanent billing code for ABA. And all that means is it makes it very, very easy, efficient, fast, simple and streamlined for an ABA provider to directly bill your insurance company and you know you will be reimbursed at a fixed rate for those services.

That's what I'm talking about when I say that's the infrastructure. That's the industrial complex.

Anne: Mm-hmm.

Alicia: All these enormous profits don't accrue without attending to this kind of architecture, both the architecture of ideas that justify it but then also the technical, bureaucratic, economic, legislative architecture as well.

Anne: That's so interesting.

I have a number of follow up questions about it, and I'll kind of maybe put them together a little bit. So, we've established that it seems like Lovaas was a very persuasive person...being a behaviourist. He was able to manipulate people, using this sort of coin, where on one side there's fear and on the other side, there's hope. So many people were being institutionalized that were autistic and had intellectual disabilities *and* there was a movement at the same time that Lovaas was working. There was the movement to de-institutionalize and it was an effective movement for people with physical disabilities and less so for people with intellectual disabilities. It was starting to move the needle a little bit on institutionalization and Lovaas

would argue that... I mean directly, in his feature in Life magazine for example, that “if you don’t subscribe to my program, your kids are going to be lying in an institution in shackles”. Like he literally was saying this, right...

Alicia: Yes.

[20:00]

Anne: ...”and I have the magic, promised way to bring your kids out of the institution and deinstitutionalize”. Meanwhile of course, those of us who have looked at his work know that he actually took a lot of the tools from the institution and just moved them into his clinic, such as electro-shock torture, and they continued to do so...and they continue to condone it, you know in the industry [today]. He had this sort of flipped coin, between fear and hope. Like, ramp up the fear and then say, ‘and we have the answer’. And this is such a common thing in all sorts of scams.

But I’m wondering, my first question and then I’ll give my second question after: What was going on culturally, other than the deinstitutionalization movement, what made people susceptible to this idea that behaviourism was going to be the solution, or *the way*? Was it just that Lovaas was so persuasive? Or were there other factors going on in the culture that made people really open to that kind of argument, or [were there] other players? That’s my first question.

The second question I guess is related to that which is: how on earth did the ABA industry persuade the American Medical Association to create this [insurance] code, and regarding other competing systems like Psychotherapy, Occupational Therapy, Speech Language Pathology – why did they get kind of left in the dust?

Alicia: So, in terms of what was going on, I think there was simply a lot of failure on the part of -well for my field, education, for example, to offer anything whatsoever to autistic people in schools. There was just a genuine failure of imagination, a failure of commitment, to really be thinking about and offering useful ways of thinking about educating autistic children. They were really just abdicated to the [residential] institution. They were left [behind], and at the moment when Bettelheim’s ideas were being culturally very, very rejected by families. I will say that it’s not just that families *bought* this, it’s that the families and the behaviourists began *working together* in the mid 1960s.

Anne: Mm-hmm.

Alicia: It's not like the behaviourists decided to go out and groom a bunch of families. I don't think that's accurate. In following on the *Life Magazine* piece and other as you said public relations (PR) events, Lovaas was savvy – just as Skinner was before him – Lovaas was savvy in terms of media, in terms of rhetoric, and savvy in terms of PR.

Lovaas began attending parent meetings – National Association of Autistic Children which is currently the Autism Society of America...he attended with Bernie Rimland. They kind of teamed up and the families (and by that again I will say the non-autistic parents of autistic children) really, really wanted *anything*, right? They were falling on him with gratitude, I think because they had literally received *nothing* from anyone, other than blame for their child's disability. And the whole psychotherapy debacle before that had been about "well, if we do enough talk therapy, perhaps your child will cease to be autistic because we may be able to undo the trauma that *you* levied upon your child which induced the autism," which of course is nonsense, right?

So, in reaction to being blamed for their own kids' support needs, and not having received anything really educationally from schools, families were, I think, happy to be offered anything that might be literally useful, helpful, pragmatic. "How do we get through meals without things ending up on the walls. How do I get my kid to keep their clothes on? How do I communicate with my child?" Things of that nature that... questions that families were asking.

The behaviourists, I will give them this, were willing to be very, very pragmatic. But they were also very savvy about wrapping things up in hope.

The other thing I will say is that in the late 60s, early 70s when the behaviourists and the families started sort of working together and building this complex, Lovaas was very tepid about hope. He didn't start promising the sun and the moon and recovering your child until 1987. Everything prior to that, he spent a lot of time trying to dampen hopes..."we'll do the best that we can, I make no promises, I hold out little hope, there's maybe a 1 in 10 chance that I can help your child". Which is a very far cry from "a 1 in 2 chance that I can help your child," which is what he was offering later on.

Remind me of the second part of your question...

Anne: Yeah, my second question was [so] *parents* were being persuaded which I think, you know it's a really good point, [ABA was] just the loudest and kind of the only ones...and the most organized, right? But, how were then *policymakers* and [institutions] like the American Medical Association persuaded...

I just want to preface this by saying that the evidence for ABA is really sketchy and..

Alicia: Yes.

Anne: ...And when you look at what they say even that they achieve, it's not necessarily something that is something that we really *want to* achieve which is like, total compliance and submission... not my goal as a parent, although I understand why parents end up using ABA, because it's the only system offered to them.

You know just as an aside, in Canada even though we don't have a lot to do with insurance companies here, we do have codes, and ABA is really written into the DNA of our social health care system now; in some provinces it's the only funded therapy. Until 2019 in Ontario, even Speech Pathology, AAC and Occupational Therapy were *not funded*. It was all just moved over to ABA. Parents, if they wanted to do *anything* for their kids, they had to do ABA or pay out of pocket. So, it became so like normalized that everybody just assumes it must be the best way.

But, of course, when you look at the evidence, you can see the evidence of benefit is extremely biased and poorly designed and there's also evidence of harm, or they often don't even study the evidence of harm. Anyway, I just want to clarify that it's not in any way a slam dunk in terms of being useful and even if it were the uses of it are questionable as well.

So, the problem that we have is that alternatives have not been able to flourish, even when families want them because [the ABA industry] has this stranglehold on funding and that has to do not so much with parents, it really has to do with policymakers and organizations like the AMA just kind of going along with this pre-packaged service known as ABA.

The second part of my last question was then: why? Why are all the policymakers and insurance companies--and the social insurers here and the federal and provincial governments here and the state governments there—[supporting ABA]. It seems like Autism Speaks kind of marches into their office and says “we have to have this covered under insurance, families have to be able to get more than \$50,000 a year from their insurance company for this” and the price of it just keeps going up and up and up and it's 50 and 100 times and 200 times greater than other services like Occupational Therapy.

How did it get to the point where the systems--whether it's insurance or state funded insurance like in Canada--how did it get to the point where systems were just willing to give the industry that much money? I'm thinking especially now because we're living in these times of greater austerity and insurers are not great at providing even like, needed cancer surgery or lung transplants or things that people need to live, but yet there's this almost unbridled capacity to fund ABA. So, what's going on with that? Why is it like that?

Alicia: So, within the US it is a slightly different consideration, I will acknowledge, than in places with public health systems. But you put your finger on the button when you said that Autism Speaks waltzes in and all of this money starts falling around. So, the other sort of pivotal moment that really, really launched this into, not just a burgeoning set of industries, but a

skyrocketing, proliferating, ridiculously proliferating set of industries was 2005 with the entry of Autism Speaks. And the reason... I mean we all know that that's obvious, right...they came in and a lot of stuff started happening, but what we don't always think about is how and why. Autism Speaks as you know was founded by Bob and Suzanne Wright and Bob was the Chairman and CEO of NBC Universal. He's a media mogul...

Anne: Mm-hmm.

[30:15]

Alicia: It's a media company. Yes, it is technically a non-profit with the IRS. They have a form 990; I've gone through all of them in great detail. It doesn't operate as any ordinary non-profit does. It operates as a global multi-platform international media corporation. And so all of the rhetoric that the behaviourists had been working on and proliferating and getting people to consume...all of that just skyrocketed when the media moguls and the capitalists came in with Autism Speaks. But to go back to one thread from your earlier question is, why do people buy this, right? Another reason they buy it is the branding of all of this as scientific...

Anne: Right.

Alicia: ... Right, and I talk at length in the book about the distinction between Science and Scientism. And Scientism is essentially the discourse or the ideology of science being used for branding purposes, right? Being used to legitimize a venture--in this case, what is inarguably a commercial venture. Because they went to such extraordinary repetitive lengths, to brand ABA as scientific during the 80s and 90s...it's like if you say it often enough it becomes true, right? This is a very, very old, tried-and-true political playbook in the U.S. It's a very *cultural politics* playbook. Culture war politics, I should say. You brand something as "scientific" and you're going to say it often enough and it's as good as if it were true.

Anne: Right.

Alicia: ...Because nobody goes back and reads the original scientific literature and sees the flaws in the design. Everyone has simply consumed articles in the *New York Times* or in the *Washington Post* or on *Good Morning America* over and over and over again, that--without much elaboration or legitimation--simply characterize this particular method as scientific.

Anne: I think the people that are reading the papers are in the neurodiversity movement and that's kind of the people that are being skeptics...and in the inclusion movement as well, and in the broader disability rights movement—these are the people that are looking skeptically at this system and saying: “Why don't we apply a disability rights lens to this? Why don't we take some clues from the disability rights movement in terms of access and inclusion and move [to] that?”

I think the neurodiversity movement is going to be a really powerful market disruptor for this whole system, combined a little bit with increasing austerity because it... I think the ABA industry might fall on its own sword because they charge so much money for their services.

Because we're running short on time, I want to get to my last question which is about parents. Because parents, for the most part, want to help their kids and like we've been talking about, the ABA industry is very persuasive that only *their* products and services will help--and it's really hard to see through the hype.

So, I thought we could take a couple of minutes just to talk about how parents can tell the difference between a service that's going to be inclusive and helpful for their child and a service where there could be some red flags where there would be problems with it. Do you have any insight based on what you've been looking at?

Alicia: Well, first parents should probably be aware that in the context of the U.S. specifically (and you'll help me extrapolate to a Canadian context)...within the U.S. educationally you are almost certainly going to be presented with ABA as the “first, best, most appropriate and most scientific” option. You're going to have to do your homework if you want to do anything else, or other or different, or not do that at all. You may also have to prepare a defense against people suggesting that you are somehow *neglecting* your child by not giving them this “wonderful, scientific intervention model”. And again, schools in the US have largely abdicated the teaching of autistic children to ABA consultancies.

Anne: Right.

Alicia: They would rather pay money to these consultancy firms who come in and say “we've got it covered, we know how to do this, you don't even have to think or worry about these kids,” and then run their segregated classrooms with their ABA programs.

What I would say to parents is first and foremost it's important that you understand that this is a commercial industry and that your child is a commodity in this industry. Your child represents

the possibility for that consultancy to fill a seat in one of their classrooms and get a fair chunk of public dollars diverted into their revenue coffers, simply because that's how the system is set up to work most fluently.

Everyone is going to say, of course, that they have your child's best interests at heart and I'm not so cynical that I won't say that most of the time that is probably actually true. Most of the professionals that are going to be working with your child probably do have your child's best interests front and centre as something they're thinking about, something they're committed to.

What I would say is *that's not the only interest at play*.

Anne: Right.

Alicia: ...and that person's employer has other interests that go beyond what is best for your child. That person's employer has bottom line interests, right?

Anne: Right.

Alicia: So the first questions I tell parents to ask is: "this provider that's contracting with the school district to provide supports for the child, is it a for-profit or non-profit?" If it's a non-profit, ask to see their form 990. Ask to see their tax forms. Do they have an LLC component that is a for-profit component. Ask! Because if they do, you deserve to be aware of that.

You also don't have to be completely pressed into making this decision right here, right now. You have a little bit of time to inform and to educate yourself. The other thing I always tell parents is (as you pointed out) look to autistic communities for information...because the information that you're going to get from your district, probably from your pediatrician and certainly in the US, from your state level non-profit autism parent support group--is probably all going to be provided by the ABA industry, right? And so there's going to be a certain monopoly. The information you get access to through those channels has already been curated for you.

Anne: Yeah. People need to think outside the box and look outside the box. I'm going to put a resource list on the podcast website (noncompliantpodcast.com) of some of what we've been talking about in terms of helping parents make choices and understand, to think outside the box and also be able to *advocate* outside the box if they want something different than what we've been talking about today.

Alicia's book looks at so much. It's definitely worth reading... an incredibly interesting book. I thank you so much for this conversation. It's been so interesting and important and I hope we can continue it. And that people will check out the book and learn more about the issues.

Alicia: Thank you so much Anne for the opportunity and I look forward to talking more.

[Jazzy synth pop music]

Anne: I was speaking with Alicia Broderick, a professor of education at Montclair State University in New Jersey and author of *The Autism Industrial Complex: How Branding, Marketing and Capital Investment Turned Autism into Big Business*.