

* **Content Warning:** institutional settings, abuse

The role of private equity and lobbying in ABA funding: Talking with investigative journalist John Summers

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Transcribed by Julie Ann Lee

(Theme song – soft piano music)

ABK: Welcome to Noncompliant. I'm your host, Anne Borden King. Today I'm speaking with John Summers. John Summers is founder and president of Lingua Franca Media Incorporated. He has a PhD in Intellectual History and has written, taught and presented extensively on topics in culture and history. His recent exposé in *The Nation* looks at the unusual relationship between private equity companies and a form of autism service – Applied Behaviour Analytics (or ABA) in Massachusetts where he lives. Today, John and I will be talking about the business of ABA and the problematic industries built around autism.

John, welcome to the show!

JS: Thank you.

ABK: You write in *The Nation* that: "In a flurry of legislative acts passed between 2010 and 2015, Massachusetts, ... became the 22nd state to [mandate insurance coverage](#) of Applied Behavior Analysis (ABA) as a behavioral health benefit for autism. The state's market for ABA services has been booming ever since....ABA is now the default standard for treating autism across a range of settings from school to clinic to home. (The autistic child of a family without the money to pay out of pocket will receive nothing but ABA in Massachusetts.)"

What you describe there is something that's happened in numerous states and also here in Ontario. The ABA industry has established this market dominance, so parents don't have a choice of services anymore. They *have* to do ABA or pay out of pocket for any other services, if they have that economic privilege. So, what's happening here? Is this becoming a monopoly on public-funded autism services?

JS: It seems that it is - practically speaking it is. You use words like market dominance but it's beyond that. And it is coming at the expense of families who don't have the ability to pay out of pocket...which, I am one of them. I had a Floortime specialist in this weekend to evaluate an option for my family and the cost was \$150 an hour which is prohibitive I think for me and for most people. The odd thing is that when Massachusetts did this [mandated ABA] even though

there was a lot of celebration and because the priority is on access, and to the extent that they intended to make available treatments to families to give them something.... I think the intentions were good but then they could have provided access to more than ABA.

They could have in fact, included funding for development of alternative service models. They didn't do any of that. They enshrined ABA as a default standard, so that's what we have now, and not the other possible alternatives such as Floortime (of which I know little by the way, I should say and I'm not shilling for it or anything else except I want innovation and some competition.) We have families moving from other states in New England in order to access services here in Massachusetts because Massachusetts is being held up as a leader and as doing something great, expanding the access which again is a good thing, better than some other states which offer very little to families but it's created this situation where there's an enormous amount of money that's available and that **what ought to have been a service model has turned into a financial model.**

So, what caught my attention was not the private equity sort of expanding in this field, it's more a specific question of what exactly private equity see in this particular social policy that makes it attractive. And that's a scary. It was a scary question.

ABK: Yeah. And what is that? So they've kind of muscled out all of the competing therapies-- many of which are evidence based don't get funded anymore and only ABA is being funded, and then you have these equity groups coming in. Let's talk about that. What's going on there?

[5:00]

JS: I noticed this first again as with most of these questions for me on a personal basis when a few of my son's **ABA providers I noticed had been acquired by private equity groups** which kind of sent a chill down my neck because I don't typically associate private equity with human service and care.

ABK: Mm-hmm.

JS: The main one at first was the Center for Autism and Related Disorders (CARD) which was also by far the worst service provider we've ever had. When I noticed the scale of the acquisition, \$700,000,000...that's a lot of money. And it's a big group. Then it happened with a few of the other providers as well. So I began to ask questions *and if my questions had been answered I might not have needed to write the piece.* I eventually reached the Executive Director of the Autism Commission in Massachusetts – a very nice person named Carolyn Kain and she frankly told me (and which I quoted her in my piece) that she doesn't know anything about it. So that was pretty frightening because that's the main policy making ...

ABK: Yeah.

JS: ... body in Massachusetts for autism. So, I'm giving you a frustrating answer to your question because we don't really have any information. There really doesn't seem to be any entity, government level or otherwise, tracking this issue.

ABK: Right. Tracking it, but the policymakers are the ones making decisions about it right?

JS: Well, they've already made the decision. They adopted ABA as a result of an intense lobbying campaign by Autism Speaks and they allow the lobbyists to do their thinking for them.

ABK: Mm-hmm.

JS: So what we're seeing now are the consequences of the practical monopoly that they enshrined with the insurance reforms and the state has not nearly caught up with the transformation from a human service model into a financial model. I just want to stress the distinction between the two because it has become a financial model now.

ABK: Because of the involvement of private equity and other...

JS: Yes.

ABK: Uh-huh.

JS: Yes, yes. Well there's an enormous amount of money being made by behaviourists in Massachusetts and I expect elsewhere. There's the kind of playbook: you start an agency... you don't have to have any credentials, you could just be the administrator, but you raise a lot of money, start an agency. You reach 100 clients or so and generate revenues about \$10,000,000 a year and at that point you will begin to get solicitations from the [equity] companies, and there are companies now that have emerged in order to make this transition smoother. Now, of course also funded by private equity companies you can basically package your business and then flip it or – they call it *recapitalize* -- for bigger bucks.

ABK: Mm-hmm.

JS: And take away several million dollars. And given the fact that there are many more families that need these services than there are ABA providers, the market is terrific right now. I won't say it's easy to do but it's not difficult to do for any enterprising administrator who wants to make some money in the entrepreneurial field of autism.

ABK: Mm-hmm.

JS: There is a behaviourist named Paul Does who I quoted in my piece. He was very frank with me that there are a number of especially old line, older generation behaviourists who are quite upset this is happening and it was his comment to me that struck me so forcefully that other than being a physician, autism – going into autism is the single best way to make a million dollars in the human service field.

ABK: Wow.

JS: I don't know what would substantiate that but that's what [he said].

ABK: And you don't even need to have expertise or specialization just to open them...people are opening the clinics, hiring the BCBA's and then basically turning it into a commodity.

JS: ...or even one BCBA. In Massachusetts what they call Registered Behaviour Technicians don't need to be licensed so it's possible to hire one BCBA and then hire a fleet of high schoolers with laptops and send them into homes, and that's happened to us. That's basically the CARDS model.

[10:00]

ABK: Right, okay.

JS: And so the clinician sits in the home with the laptop, goes through a series of questions; plugs in the numbers and then leaves. *There's no effort to make a connection with the child. There's just measurement.* And measurement and accounting – that's of course all very important to financial models that rely on stockholders and boards [who] like to see numbers. Everything has to be measured and crunched.

So they're able to allege improvement with the statistics which is a major part of this whole sham.

ABK: Yeah, yeah. It's part of the smoke and mirrors and maybe it's one of the reasons as well that they're able to be so persuasive with policymakers because if you look at insurers the way that the state mandated it for insurance coverage, but *only* ABA, it's very similar to Ontario where only ABA has been funded here. They just opened [government funding] up to a little Speech Language Pathology and OT which is like, 'oh thank you!' The thing that every family needs, people had to pay out of pocket because ABA established this monopoly with the policymakers.

We of course have social insurance here, so it's happening a little bit differently but it's the same type of lobby where they persuade the policymakers that this is 'the only evidence-based therapy' and they persuade the policymakers who maybe aren't putting a lot of time or energy into this, they just take the package and go 'Good, now I've made everybody happy, we'll just do this ABA thing,' without any nuance or understanding that there are so many different approaches that are evidence-based....that are not being funded, that families want.

It's sort of amazing that they've been able to influence policy that strongly and it's hard to understand how it's become so built into policies for so many states and provinces in the way that it has.

We have records of course...I looked up the lobbying records and the ABA industry makes big lobbying efforts to target specific policymakers and politicians on this, right? So, that's a part of

it because if there was some scrutiny from the government, we wouldn't be in the situation we're in, I don't think. Is that right?

JS: Well, there should, in principle, be no problem with establishing a mechanism for scrutiny; because everything is measured, there should be a way to measure collective efficacy. In other words the kind of obvious question is "does it work?" which I raise in the piece. The subsidiary question is "for whom does it work? For how long?" And so forth. But the basic question is "Does this method work? Or does this matrix of care or therapy work?" And I found in Massachusetts, no one is trying to answer that question.

ABK: Hmm.

JS: And there's no data being taken across all the different areas that either the government or the private insurance is funding as ABA, and there's no longitudinal data because there's nothing to compare it to.

ABK: Mm-hmm.

JS: So we've had this really kind of aggressive experiment with childhood autism in Massachusetts now for half a dozen years or more. Like some point we should find out if the investment has been worth it.

ABK: Mm-hmm.

JS: And yet, we have no way of finding [an answer to] that question right now. And of course even though the [ABA] model stresses measurement and evidence, the profession doesn't want to see anyone independent looking at a larger... You're far ahead of me on this but.... I'm still surprised by these things when I'm going through and finding myself. But no, they don't want anyone to sort of try to figure out independently. And not just in a collective sense, a kind of state-wide sense, but also in an individual sense.

One of the things I learned was that the reason that so much **bad behaviourism** is happening is because *the mechanisms paying for it are totally separated from mechanisms of evaluating it*. I even called our insurance company to ask how do they know it's working and they don't have any mechanisms at the insurance company to find out. They just add up the numbers to see if the number of hours are matching up with the level of billing and that's pretty much it, so...

[15:01]

ABK: Is that because the industry develops their own benchmarks and just kind of foists them on the funders, or...?

JS: I don't think they need to make the argument anymore. I think they're making the argument from authority. 'Look, see the government has endorsed this model,' so I don't think they need to make the argument anymore. And that's frustrating because when you try to have a discussion with clinicians--I have many times--you get the same set of pat answers, along with

the kind of disinclination to go too far.

Because, why should they need to make the argument? There's no competition and they've been endorsed by the state legislature.

ABK: Right. Are there ways to get our legislatures to be accountable? That feels like one of the first steps that we need to take to kind of take on this *monster* here that we're dealing with. To talk to the policymakers and develop some sort of way for them to do some critical thinking about this. Is that part of the problem coming from the legislatures that have just kind of rubber stamped this whole thing?

JS: I can't believe you just used the phrase 'critical thinking' and 'state legislature' in the same sentence.

ABK: (laughter)

JS: You may be more hopeful than me! I mean I think that there's an undercurrent of rational force that has brought about this situation and it's very simple and very sad. Rates of diagnosis are going through the roof. Social policymakers have no clue why or what to do about it. So, when they're presented with a paradigm that seems professional, scientific, has this sort of pedigree in a way that other paradigms and service models are not presenting them with, they're going to select that because they want to do something, and they don't know what else to do.

So I don't think that there's a possibility of discrediting ABA at that level any time soon, because there would be too much pushback. The question is 'well, what would you like us to do?' So there needs to be an alternative solutions to the same problem. That's difficult when there's so much money in the system.

ABK: Well, I don't think that Floortime and other providers really have the same way to promote themselves. They're just not as organized.

JS: I mean you can look at it in one of two ways. ABA is a profession. You can look at it like we're stressing it like 'oh it's amazing how strong they are', or you can look at it from another perspective and think how amazing it is that it's taken them so long to achieve this. Still only about half of the US states endorse ABA as an insurance mandate. I mean it's been around for more than half a century.

ABK: Mm-hmm.

JS: And so the question is who is still contesting it? How have they managed over the years to deal with those persistent struggles and questions about their reputability? I think it's a lot to do with how they behave now and how insulated they are from peer professional criticism.

ABK: Hmm.

JS: Does that make sense?

ABK: Yeah, absolutely. I mean I sometimes wonder if it's going to be like a David and Goliath situation where it's so big that really it's just going to take a little slingshot to kind of collapse under the weight of its own...especially now with the new involvement that you're seeing with private equity.

JS: Well, if it happens it would happen through the insurance companies.

ABK: Mm-hmm.

JS: The insurance companies I think are probably the pressure point because insurance companies are created in order to deny claims and to the extent that they're being forced in these...I think it's 29 states now, including Massachusetts, and probably Ontario too, to pay I think eventually they're going to question 'why and how much?' Because in Massachusetts we have no dollar limits or age limits on the service which is remarkable. I don't know how many other states are like that.

But seeing the money go into private equity hands is the kind of transfer of wealth they may object to. What form that would take or what it would take to make what the limits are, I don't know. But unfortunately I think change is going to come about not through exposés of substandard clinical care and abuses but through the money.

[20:10]

ABK: Yup. That bottom line. I think, too, in countries that have social medicine, it's coming through austerity. I mean our governments just don't want to pay that much money into our public health system. So that's one reason why it's starting to get chipped away. It's probably why [ABA] hasn't been adopted in the UK or Scotland or other places, because of the amount... almost like it's the system's own demands for number of [clinical] hours and billable hours is just far too great for most social health care systems to manage.

And so if someone comes along with an alternative they could be a disrupter to that market, at least in Canada and Europe.

JS: Yeah, that would be great, but here's what I think we have to overcome – that's what I've noticed if you don't mind me saying so about ABA, what I've noticed because I've moved myself from a position of reluctant acceptance because all of my son's providers recommended ABA, (again because there's nothing else but they recommended it with enthusiasm). So I set to do it with a kind of resignation and then observed it for a few years in my own home and then did some research of the kind of corporate structure and financial model and have moved really from a position of—I'm on the verge of hostility. I'm still at the sceptical level but I'm getting to the hostility and a lot of that has been produced by talking with ABA people who are *completely immune to any sort of self-reflexive consciousness*, and I think that's really important. It comes across in the public presentation in terms as well as the lobby.

ABK: Mm-hmm.

JS: The process by which they have established themselves has been pretty familiar, even though they have a very high degree of professional class consciousness. As high a degree as I've encountered in any other profession.

ABK: Hmm.

JS: And I think the kind of sociological aspects of how they exist in the world as a profession are really important if you try to engage with them.

ABK: Right.

JS: I thought a lot about that, not so much in *The Nation* piece but the way they established their jurisdiction back in the 1970s by discrediting alternatives, which they continue to do, like the naturopaths in the 70s and psychiatry. They brought a pretty distinct advantage and benefit in the 70s which is that they were rejecting drugs...

ABK: Hmm.

JS: ...and at the time they established their jurisdictional domain as being able to effectuate some improvement *without* the use of drugs and that was very appealing to a lot of people at the time.

ABK: Mm-hmm.

JS: Then--and this is the part that I find most frustrating--they sort of relabeled everything that they were doing from what was and still is basically behaviour modification in culture to a fancier term called *Applied Behaviour Analysis*.

That created a thesaurus or glossary of jargon and that has two advantages. It discourages 'amateurs', parents actually asking questions and it also improves quality of the recruiting. Because right now there's several hundred highly technical jargon terms in the textbook which they need to master for passing the licensing examination for becoming a BCBA and from talking with them, I've...they all say that mastering the jargon (the terminology) is the most difficult part of the exam.

If you think about that, it's really kind of perverse because they all admit that the principles are very common sense they say. They're very ordinary principles.

ABK: Mm-hmm.

JS: There's something that you the parent might do normally, but then they need to master all these crazy re-labelling jargon terms as if they were doing something so sophisticated it can't possibly be stated in plain language.

ABK: Mm-hmm.

JS: So then those who pass tests become credentialed BCBAs are then the ones who are most likely to defend the system, of course, as in any profession. They've taken the time to master, or at least memorize the terms and then they defend the 'professional integrity'. They'll tell you on the one hand that everything is very ordinary and at the same time it's so sophisticated you can't understand it. In other words they become 'experts'. Oh yeah, I'm sorry if this is obvious, it's taken them 50 years to do it...

[25:10]

ABK: Right, right.

JS: ...but they've done it. So once you've established your jurisdiction and your jargon, then you get a toe-hold in the colleges and universities and then on those bases then you approach the elected officials and say 'look, we're a fully-fledged field'. The rest is kind of lobbying.

But I think the tell-tale problem is when a professional discipline matures in this way, with jurisdiction and with jargon and with a kind of toe-hold in universities, you typically see a couple things happening. You see the basic research designs becoming more sophisticated and you see the research results being replicated and you also see over time a lot of negative results being published and inconclusive results being published, which is after all what science mostly gives you. You see the jurisdictional efforts relaxed a little bit and so you have other disciplines that are being invited in. So you might see collaborations with psychologists or statisticians or cognitive scientists. You see a kind of self-reflexive professionalism develop in a mature discipline where you have confident discussion of conflicts of interest for example. And then you also see overtures to the public in open access journals for example.

And [they] followed the playbook to get themselves established but then they stopped and they didn't mature; they didn't go the next step and I think that's a really important fault line. They still use the single study research design, there's very little direct replication, at least any that's been independently verified. They're absolutely manic about keeping apart the misunderstanding that they had anything to do with psychology- God Forbid.

ABK: Mm-hmm. Right.

JS: There's no collaboration that they're really interested in. The research is mostly funded by the government and distributed to public colleges and universities and yet the top dozen ABA journals are published by *three* for-profit companies. And it's barricaded behind pay-walls, so there's no overture to the public either.

So you get this odd kind of hyper-professionalization without the maturation that one would expect from a typical trajectory. You get a kind of paranoid style that they have that deflects criticism, so the whole thing seems to hang together on a couple of basic kind of simple binary distinctions. What they're doing is 'science' and what everybody else is doing is 'non-science'.

ABK: Right. 'Not evidence based'.

JS: Not evidence based. [In their view] the people who criticize behaviourism are 'emotional'; people who endorse it are 'analytical', right? I've seen this come up hundreds of times and I know we probably don't have time for it, but I think a lot of this is an inheritance of the pedigree of **B.F. Skinner**.

ABK: Hmm.

JS: Skinner is the guy, he's still the number 1 most cited in the [ABA] textbook, the current edition and he established what he himself called a *cult* back in the 1950s and all the stylistic tics that ABA demonstrates today, most of them can be traced back to Skinner's own personal style which was, "I'm a great man, a great thinker, on the level of Darwin, and the rest of you people are idiots." That's more or less what his deal was, even towards the very end of his life.

And, I mention him because he was a Harvard University-educated psychologist, one of the most famous 20th century psychologists, right here in Massachusetts... in Cambridge, right in my backyard, so he looms over this. I think it explains a lot of the self-presentation of the discipline. The sad irony is that nobody to my knowledge in the United States at least, any top forty or maybe even top hundred colleges or universities thinks Behaviourism is anything more than a relic.

[30:15]

ABK: Right.

JS: I mean it's not intellectually respectable. There's no, I mean cognitive science clearly, vanquished behaviourism in the 80s.

ABK: Yeah. Mm-hmm.

JS: So, why is my son getting a service model that is based on the whole philosophy that was discredited 40 years ago? It is really strange.

ABK: Yeah, your son and millions of kids and adults and even expanding into the prisons and other sectors. It's- I have a question for you about this mystique that they've built around themselves and this echo chamber that they've built within their own industry and the way that they've kind of walled themselves off and present themselves as the 'only way'. I've heard people describe it as cult-like, would you agree with that kind of assessment?

JS: A cult or cult-like?

ABK: Cult-like, yeah.

JS: I don't know. I think you're either a cult or you're not. You know, cults tend to self-destruct, so, no. I don't think so. I don't think that's probably a very apt term because I don't...you seem

to think maybe there will be an implosion at some point. There may be but that maybe because of market dynamics rather than a kind of exploding... Although I'm thinking about this as you ask me, maybe?

If it is a cult, it still does revolve around Skinner. I mentioned in my *Nation* piece this really absurd video – [promotional video](#) that appears on the website of the Massachusetts Association for Applied Behaviour Analysis. I urge you to look at it if you haven't because, there's a giant – gigantic photograph of B.F. Skinner, right in the background during most of the video, as if someone would know who he is, and it's a little strange. I would I guess.... calling it a cult, making it... sort of demonizes it a little bit.

ABK: Yeah, yeah.

JS: I think it does, as I said earlier, I think it is more profitable to think of it in sociological terms as deviating from the normal process of maturation for a professional discipline in the United States. That way at least it can be pushed in certain directions. The research results should not be barricaded behind the walls, they should be made to address their conflicts of interests. Why should a cult be asked any of these things?

ABK: The human cost in all of this is obviously is people haven't been given access to the types of services they need as a family. There's a huge cost to that and there's certainly been....for anyone who's not really up on this there's really ABA wants to position itself as a standard – *The Standard of care*, but it's really a contested system, but I don't think policymakers understand just how contested it is... just how much resistance there is in the community or how much people in the community want alternatives to ABA.

And then there are the issues like at the Judge Rotenberg Center or other places like that where we have these very extreme versions [of ABA] in residential institutions. You've argued that the financial model of human services in Massachusetts basically ensures that there's no incentive for provider agencies to curtail abusive practices. Could you speak to that a bit? I think you're writing about that now.

JS: Yeah, I was interested in [the Rotenberg Center]. It's only about 20 miles from my home in Massachusetts. And I wasn't aware of it for a very long time and once I became aware of it started to tell my friends about it. None of them believed me. They had to look it up. So, your listeners understand a little bit about it. It has a long history that has never been written – I think that is also quite curious.

It was started again by the protégé of B.F. Skinner, **Matthew Israel** back in 1970. A man who got his Ph.D. in Psychology from Skinner and was endorsed by Skinner at various points in the 1980s. It's to some degree a Massachusetts story.

Before they started using electric shocks on autistic children which has been disclosed, they were spraying ammonia vapours in the faces of these kids and they were shackling their legs and their arms and they were putting hoods over them- welders' helmets over them so as to induce sensory dysregulation... (Sarcastically) which is exactly what you want to do with an autistic child, right? And at least six persons have died there.

It's also a California story because there was a sister institution in California that started in 1976 and ran into very similar troubles-- which is to say torture and death--and was only recently closed down after allegations of child abuse. The story has never been told. There are lots of interesting core issues about ABA, punishments and rewards that are central to the story of what used to be called the **Behavior Research Institute**, now called the **Judge Rotenberg Center**, but it is as much a legal and political story as it is a scientific story. And that can demonstrate in many different ways from the hiring of former governor **Pat Brown** in California to lobby his own son in 1980 from shutting it down, to the hiring of **Rudolph Giuliani's** lobbying firm today in New York to ward off efforts to remove it from approved out of district special education schools in various states.

In Massachusetts we have this thing called a charitable immunity statute and if you look at the states that still have a **charitable immunity statute** they present a real problem for organizations that are organized as non-profits which is the principal alternative to full profit, private equity adaptable entities. Most states have done away with the charitable immunity statutes but what it means for those who haven't including Massachusetts, that the organization can be sued, but the liability for any tort actions is \$20,000.

This is the primary reason why the Judge Rotenberg Center has remained. There's no legal effort to hold it accountable in a financial sense, likewise with the other provider agencies that are organized as non-profits. There's also no financial incentive for them to hire an appropriate staffing ratio or to pay their direct care workers a good wage so as to reduce the possibility or prevent abuse before it happens. Of course the organizations can be sued, and if they lose they'll pay \$20,000 or I should say *we'll* pay \$20,000 – taxpayers, that is, because of course everything is publicly funded.

ABK: Mm-hmm.

JS: Otherwise what I think would be possible to do with ABA... is to turn the imprimatur of state monopoly against them, file public records requests for billing records, properly redacted, and find out whether there's a larger fraud being perpetrated on public money.

ABK: Mm-hmm.

JS: ...so it's hard to do that in Massachusetts because at least again to the extent that they organize this as non-profits because there's no fear of a lawsuit. It could potentially be done in other places, especially other states that have good public records laws.

ABK: That's really interesting. So they've kind of got everything set up for themselves in such a way that they can't really be contested in any way.

JS: Not that I've seen, unfortunately. Not that I've seen, but the way that social change happens is mainly through public opinion, as much as we like to think that the mechanisms of history are outside our grasp and they're codified into law and public policy, I do think that the public opinion lies behind both of those things... and the way you influence public opinion is you do what *you're* doing and what *I'm* doing and you tell the stories and make the analysis and you put it up hundreds or thousands of times again and again and you develop a kind of threshold of awareness.

We're dealing with an organization or an entity that is a service model again that's taken them half a century to get into 30 states, so that should tell you something about the vulnerabilities. They're manifold.

[40:35]

ABK: Yeah, yeah, they are. In order to challenge that system one doesn't need to have the same amount of resources or authority that they have, really. It comes down to conversations to make that change because it's about changing people's attitudes and approaches, is that right?

JS: It is, and what's been very impressive and very heartening about the recent history of autism is hearing from autistic people themselves, I mean they're the ones that are making the case against ABA most effectively and forcefully, that I've seen, and they are arguing that the way that they were treated by ABA clinicians and the way that ABA behaviourism more generally conceives of them is not as persons but as '**stimulus and response entities**' has been extremely harmful to their dignity as well as to their idiosyncrasies and distinctiveness as persons.

I think that strain of criticism is probably going to be most effective out of all of them. So, that should be encouraged and it's wonderful to see, of course you have another set of problems for persons who can't speak [about what's happening] and that's a whole other kettle of fish as they say, but it's really interesting to see the autistic persons who have been through ABA, read what they have written and said about it.

ABK: I think what comes after that, usually the question that comes after that that parents have is, they might say they understand the problems with ABA but '*then what?*' And I think policymakers often have the same question.

I've met policymakers about autism policy here in Ontario and their question is 'Okay well what can we use *instead?*' Then we tell them about various approaches and then they say 'Is there data to support those approaches? Is there research to support it because we can only really support things that have this huge, mega-data associated with it.' That's another thing that we have to come up against is that there are different approaches but they're not going to have

the same level – they're not going to have the same capacity of this 50 years of so called 'data' being produced about them. That gets into a whole other level of, how do you convince people to make the shift?

JS: Well, you have to change the question. The question is not how can we regard our children or family members or ourselves if we're autistic as 'problems to solve' to be adapted, adjusted; but **how do we support the development of such persons as persons?** I mean that's a human rights question, it's not a scientific-technical question and I think that's really the only way to move the argument. Because the discussion you've had with the state legislatures, I mean that's sort of a narrow way of conceiving it and that's the domain in which ABA thrives and will thrive even if you point out that the numbers don't add up for ABA, they're still going to say well, whose numbers look better?

ABK: Right.

JS: And so this is why [we ask] the question of: who does it work for? And to what are we adapting these kids? Really ...very important.

ABK: Right, right, exactly. It's not about putting in a new system to replace it that has the same end goals or end users. It's really about a paradigm shift. It's big.

[45:00]

JS: It's about widening the question from a somewhat narrow technical issue to a social problem. I think that's the way to go, to try to broaden the audience for the issue and to link it with allied issues which is why the human rights framework is important because I think that to the extent that ABA is effective it is effective on behalf of teachers and parents. And as a parent, yeah I have kind of a direct interest, but I'm more interested in finding ways for my son to rebel against me than to comply with me at every turn.

That's why I write in the piece that it's clearly a social control paradigm and it gives the established authorities a mechanism of keeping control over a problem as they see it, that is growing exponentially and threatening to erode gains in....transportation and housing and medicine... So, you've got to just change the framework of how we approach the so-called *problem* that's being solved.

ABK: That's so interesting and has been such an interesting conversation. Thank you for coming onto the show and speaking about your work and we're looking forward to seeing more work from you as well.

I was just speaking with John Summers. He's the founder and president of Lingua Franca Media and we've been talking about ABA, particularly in Massachusetts where he lives.

Thank you so much John for being on the show.

JS: My pleasure. Thank you.

(Theme song - soft piano music)

ABK: You've been listening to Noncompliant, the podcast. I'm your host Anne Borden King. Noncompliant is recorded at MCS Recording Studios, engineered by TJ Liebgott and Nathan Greavette.